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ABSTRACT

Five bulletins of the National Center for Clinical Infant Programs include articles with the following titles and authors: "Lay Home Visiting Programs: Strengths, Tensions, and Challenges" (Mary Larner and Robert Halpern); "The Post-Partum Support Project: Serving Young Mothers and Older Women through Home Visiting" (Elizabeth Anisfeld and Madeline Pincus); "A Psychoeducational Approach to Developmental Intervention" (Ruth Pearce and Shelley Gallenson); "Focusing on Prevention in the First Sixty Months" (Michael Castle); "A Chain of Enablement: Using Community-based Programs to Strengthen Relationships Between Teen Parents and Their Infants" (Judith Musick et al.); "Preventing Young Children from Failing Is America's Best Investment" (Owen Butler); "Attachment Theory and Day Care Research" (Ross Thompson); "Infants and Toddlers in Hospitals: Addressing Developmental Risks" (Joy Goldberger); "The Struggle for Control between Families and Health Care Providers When a Child Has Complex Health Care Needs" (Robin Thomas); "Individual Differences, Universal Needs: A 30-Year Study of Resilient High Risk Infants" (Emmy Werner); "Enduring Gains: A Five-Year Follow-Up Report on the Clinical Infant Development Program" (Serena Wieder et al.); "More Pride, Less Delinquency: Findings from the Ten-Year Follow-Up Study of the Syracuse University Family Development Research Program" (J. Ronald Lally et al.); "A Community of Commitment: Parents, Programs and the Early Intervention Collaborative Study" (Jack Shonkoff et al.); and "Parents with Physical Disabilities and Their Babies" (Megan Kirshbaum). Issues typically also include publication reviews, program notes, and conference information. (DB)

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Zero to Three

Bulletin of
NATIONAL CENTER FOR CLINICAL INFANT PROGRAMS VOL VIII NO 1 SEPTEMBER 1987 ISSN [illegible]

Lay Home Visiting Programs: Strengths, Tensions, and Challenges

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Visiting poor families in their homes to provide guidance, information and more recently, social support has long played a modest role in efforts to ameliorate the consequences of poverty. In the latter decades of the 19th century, well-to-do volunteers known as "friendly visitors" dispensed "moral guidance" to poor families (Davoren, 1982). In the early part of the current century, home visiting was part of the repertoire of social workers and public health nurses, many affiliated with the settlement house movement (Melosh, 1982). But it is only in the past 25 years, starting with the community action programs of the federal War on Poverty, that talented but nonprofessional members of the target community itself have been called on to serve as home visitors (Hewett, 1978; Travers, Nauta, and Irwin, 1982).

In the 1980's, lay home visiting programs are again proliferating, amid high hopes that these labor-intensive, personal program strategies can successfully link low-income families to formal services and can support them in their efforts to cope with poverty and the host of stresses it creates for parenting (Cochran and Woolever, 1983; Dawson, Robinson, and Johnson, 1982; Lyons-Ruth, Botein, and Grunebaum, 1984; Zigler, Weiss, and Kagan, 1983). Lay home visiting programs have both unique strengths and inherent tensions. For example, the programs provide a way of maximizing the acceptability and cultural consonance of supportive services, while holding down the cost of

Dorothea Lange, F.S.A. 1939, Library of Congress

The efforts described in this paper were generously supported by the Ford Foundation under its Child Survival/Fair Start Initiative. The authors thank their colleagues in the CS/FS home visiting programs for sharing their experiences. In particular, Minnie Bommer, Barbara Clinton, Lupe Manajano-Garcia, Wanda Newell, and Emily Vargas Adams contributed quotes and many insights used in this paper. Addresses of all the CS/FS programs are available from the authors.

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making individual visits to families. The strategy forms an uneasy union between characteristics of professional intervention (circumscribed, disciplined, goal-oriented, and knowledge-based) and features of informal social support (relatively unbounded, reciprocal, multifaceted, and based on exchanges of personal experience). Along with its appeal, then, that amalgamation brings difficulties that too often take program administrators by surprise.

In this paper, we focus both on the strengths of the home visiting strategy that uses lay community workers and on the tensions and implementation challenges that make it difficult to achieve the potential embodied in this approach to sevice delivery. Before addressing those implementation challenges, however, we will review the general reasons why home visiting has been so persistently popular as a way of serving poor and high-risk families. Then we will examine how reliance on lay workers multiplies many of the strengths of the home visiting approach, and will also consider the unique management challenges that accompany that strategy. Finally, we will look at some of the persistent tensions that lay visitors confront in their work with families.

The insights in this paper are drawn from the accumulating experiences of a set of home visiting demonstration programs supported by the Ford Foundation in its Child Survival/Fair Start Initiative. In these community-based programs, home visitors work to improve pregnancy outcomes, infant health, and family conditions that influence child development among a heterogeneous group of at-risk populations: migrant Mexican-American farmworkers, young black mothers in rural Alabama and Tennessee, isolated Appalachian families, Haitian immigrants and refugees in south Florida, and Mexican-American residents of urban Texas barrios. In some programs the visitors are "natural helpers," neighbors and peers of the families they serve; in others they are individuals with more education and experience who nevertherless come from a similar cultural background.

The authors have worked alongside program staff, assisting with evaluation and helping clarify emerging general lessons (Bond and Halpern,, 1987; Halpern and Larner (a), in press). The reflections in this paper are drawn from a study of program development and implementation involving extensive interviewing of program staff at each of the local sites. The Child Survival/Fair Start programs differ considerably, however, and the generalizations in this paper cannot do justice to the variations in their programs and experience.

The nature of home visiting practice

Home visits in parent support and education programs typically combine a number of core activities—information-sharing, modeling, demonstration, emotional support, joint problem-solving, and service brokerage and assistance in meeting pressing needs—in creating an approach that will foster growth and support parenting in the families served (Chamberlin, 1980; Halpern, 1986). Individual home visits usually incorporate a mix of these activities interwoven in the fabric of the developing relationship between visitor and family. The balance struck among the elements differs from visitor to visitor; the same visitor may

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emphasize different elements in her work with various families; and the priority given to each element changes over time as needs and interests evolve.

When she (home visitors, whether lay or professional, are overwhelmingly females) enters the home, the visitor typically catches up with the new mother on significant events and appointments since her last visit, discusses relevant health or child development topics, and demonstrates and asks the mother to try out infant care and stimulation activities. She may remind the mother of coming medical appointments, and together they plan the topics that will be covered on the next visit. Often the task-oriented "educational" portion of the visit is preceded or followed by a more relaxed time of sharing about social activities, feelings, concerns, and personal problems. The visitor both empathizes with the mother and helps her to come up with ways of dealing with difficulties.

Home visits represent a reaching out to a young family and do not, on the surface, require the family to actively seek help and support. They place the helping interaction in a relatively less threatening environment than that found in most agencies, although it cannot always be assumed that the home is a comfortable setting for private conversation. Home visits also give the family worker a fuller appreciation of factors in the physical and social context that influence childrearing, and they lend realism and relevance to the home visitor's demonstration and modelling of parent-child interaction and caregiving. Most important, they provide the sustained contact that allows a mutual relationship to develop. Because the program is embodied in the one-to-one relationship between the visitor and mother it can respond flexibly to the interests and needs of each family.

Home visits by lay community members

The decision of a program to rely on lay workers as home visitors amplifies many of the strengths of the generic home visiting strategy. For example, programs that emphasize the case-finding aspect of outreach often find that lay workers are well-suited to learn of and seek out eligible families, using their networks of personal contacts and knowledge of local "hang-outs" and activity patterns. Once initial recruitment is accomplished, a home visiting program continues to bring its services to the family's door; thus it can often maintain contact even with difficult or passive clients. Lay visitors tend to be accepted by families and their neighbors more quickly than professionals often are, and their persistent efforts to locate mothers provoke less suspicion than similar pursuit by many types of professional visitors.

At her best, a local visitor slips easily into the rhythm of conversation in the home. Her cultural familiarity enables her to read behavioral cues, frame her messages in understandable terms, and anticipate responses to her suggestions. She knows when she is bucking traditions, and is often skilled in the local art of persuasion. While any home visit affords an opportunity for staff to observe and learn about the family's surroundings, a worker from the community joins the program with substantial prior knowledge of the physical and social conditions in which families live. She can draw from personal experience to understand the issues confronting families. She has coped with poverty, and knows intimately its daily toll; she has heard how neighbors talk about "spoiled" infants, and listened as her own grandmother taught her about childbirth, remedies for fever, and signs of good health in babies. She is not suprised by the problem of the beliefs of the families she visits, and her empathy and understanding often make her suggestions more welcome.

The relationships developed in lay home visiting programs resemble the informal helping relationships that exist within natural social networks (Gottlieb, 1983). Peer helping is usually reciprocal, and while lay visitors do not request asssistance from the mothers they visit, they do exchange ideas and often share personal experiences to illustrate a point and to build empathy. "Formal" lay helping, like informal helping, is often multidimensional, integrating emotional support, cognitive problem solving, and concrete assistance in an ongoing relationship that offers continuity and stability, creating a context of confidence and trust. When a relaxed, trusting alliance develops between visitor and mother it is a mechanism of considerable power, if it can be harnessed.

Challenges of program management

As we suggested earlier, the very strengths of lay home visiting as a strategy give rise to tensions in implementation that can undermine program effectiveness. These tensions are often most pressing during the early months of implementation, but they suffuse the full range of program development tasks. Implementation challenges that are directly related to the use of lay home visitors include: (1) articulation of a realistically delimited role for the lay workers; (2) discovery of the skills and personal qualities demanded of home visitors; (3) establishment of a training system that builds on strengths and allows for the introduction of specialized knowledge; and (4) provision for a supervisor who will nurture and monitor the continued development of the lay workers.

Articulating a role for lay visitors

The first and most difficult challenge for those responsible for planning lay home visiting programs is to spell out and at the same time critically evaluate the expectations that are being laid on the visitors' shoulders. This delimitation process should be grounded in sober thought about what kinds of support tasks local community members (with several weeks as opposed to years of training, a basic curriculum, and some supervision) can realistically accomplish, and it should lead to plans for providing back-up personnel, resources, and referrals to ensure that the visitors will not have reason to overstep the limits of their expertise. In the course of their visits, lay workers come face to face with a wide range of family problems, and they often feel an internal pressure to respond. If the program provides mechanisms for linking families to professional services, the home visitors can make appropriate referrals and focus on what they do best—offering education, guidance, support, and assistance in such a way that the mother's self-esteem and autonomy are maintained.

Even when the home visitor's general role and purposes have been established, the task of supporting and educating families through home visits often (though not always) remains relatively unstructured. That open-endedness can lead to considerable insecurity for fledgling home visitors. Both the mechanics of conducting home visits and the criteria for evaluating them are often not clearly described, leaving the visitor to wonder: "Was that what a home visit is supposed to be? Did I spend too long listening to her talk about her husband's family? She looked bored when I explained the benefits of breastfeeding; should I have dropped the topic? Did I push too hard? Was she agreeing with me only to get me to leave?" It takes time before any new worker can develop the skills to manage home visits, but the process is greatly helped if expectations are clear and there are early opportunities to observe experienced home visitors in action.

Discovering appropriate recruitment criteria

Far more than in professionally-oriented services, the nature of the treatment received by each family in most lay home visiting programs is shaped by the personal characteristics of the worker. As a result, knowing what qualities to search for in recruitment is virtually as important a program development task as is the creation of a relevant and potent training program to build on those strengths. Criteria for selecting potential home visitors tend to emerge out of a trial and error process that often weighs credentials (education, prior experience, status in the community) against personal characteristics (social ease, sensitivity, maturity, and self-awareness). Different Child Survival/Fair Start programs have tipped that balance to correspond to the specific demands they make of lay visitors. For example, in two urban programs, the home visitors had frequent contact with professionals in other agencies and played a public role as advocates. These programs placed more stake than the others in educational achievement, since the visitors had to gain the respect of professionals and community leaders. The visitors in other programs focus more exclusively on interpersonal work with families; they are recruited primarily on the basis of personal qualities such as empathy, warmth, and openness. Finally, programs using lay workers as culture-brokers to link families to the mainstream service system have needed to find individuals who combine a comfortable awareness of their cultural roots with cognitive flexibility and an interest in new ideas.

Establishing an effective training system

Preservice training offers a modest opportunity to cultivate the skills that lay workers may lack, and it provides a chance for the program to discover the beliefs and values that trainees hold about matters like childrearing, human services, or family needs. All too often, however, training becomes a one-way process in which the knowledge and attitudes of the home visitors are ignored, as trainers hurry to teach them the information they are to convey to families. An overly didactic preservice program can undermine the experiential sense of mastery and successful coping that made these women a natural source of information and support to other community members. As one supervisor said,

> "We've got caring people as natural helpers and we need to use that fact. We need to give them the resources to work with—not overload... Let's not try to make them overnight professionals. They can lose their effectiveness."

If the training leaves lay workers feeling insecure about their limited mastery of the material, they may retreat to a rigid recital of the curriculum on their visits, and the key strengths of the lay visiting model will have been forfeited.

On a more mundane level, time management and documentation may pose difficulties for lay home visitors. Their role is an unusually autonomous one—in many programs they have no fixed schedule (work hours are spent in the homes of program participants, driving to and fro, on preparation and follow-up) and little objective documentation of their own. Learning to manage that autonomy is a challenge, since the prior work experience of those lay workers who have held jobs has often been in closely-supervised settings like factories or restaurants. One of the program directors puts it well:

> "When the home visitor is in the field working with a family, she is alone, without anyone to hold onto, no one to guide or to supervise her. If you have someone who is still trying to find out what a working day is like, as well as learning what home visiting is, and how to become a person of respect to the family you are going out to visit—that's a lot of pressure on a young person with little organizational experience."

Demands for visit planning and record-keeping weigh heavily on lay workers who are not accustomed to writing. Effective documentation often requires that visitors be able to interpret family needs, plan interactions and assess progress, tasks that rely on subtle skills of observation and self-scrutiny that develop only gradually in any family worker.

Providing supportive supervision

The challenge of monitoring and sustaining home visitor performance over the long term typically falls to a professionally-trained supervisor who works primarily or solely with the team of lay workers. The supervisor, who has often guided the recruitment and preservice training programs, becomes as well the pivotal individual shaping the development of the home visiting program and of the lay workers. As trainees take on their new roles as home visitors, most begin by emphasizing the tasks they find personally most fulfilling—teaching, helping out in a crisis, or playing big sister to a troubled teen. But their emerging sense of their role is also influenced by their supervisor's profesional background and personal style, since they often come to identify with her.

Supervising a lay home visiting program is primarily an educational process, not an administrative one. The success of the supervisor often lies in her ability to motivate, teach, nurture, evaluate, and reward the lay home visitors. Through one-to-one supervision and team meetings, supervisors help lay workers: to understand the limits of their role and responsibility, to use concrete observations of family life and parent-infant interaction in planning, to learn to make non-disruptive transitions between educational and supportive interactions, to deal with hard-to-like clients, to make suggestions without passing judgment, to manage the demands of needy clients without encouraging dependence, and to recognize how their own feelings and past experiences may influence their work with families. One supervisor pointed out that she works to create a growth-enhancing relationship with her home visitors that resembles the relationships the lay workers cultivate with program participants.

Tensions confronting the lay worker

In addition to the managerial challenges that the lay home visiting strategy poses to program implementors, this approach confronts the lay workers themselves with persistent, unsettling tensions. These fall primarily in four areas: (1) defining a new social role that is half-friend and half-intervenor; (2) juggling the conflicting interpersonal purposes and styles demanded by the role; (3) moving back and forth between two cultures; and (4) finding a way to build on experiences acquired through the home visiting work, in order to achieve personal goals in the wider society. Understanding the dynamics associated with each of these tensions can sensitize us to the rewarding but difficult role that lay home visitors have accepted.

Defining a new social role

As we have pointed out, lay home visiting programs incorporate elements of both professional intervention and natural social support. For all their informality, home visits are not "natural" social interactions. Cultural rules guide the behavior between guest and hostess, and these do not typically give the guest the authority to pick topics of conversation, ask personal questions, or tell the hostess how she should go about doing things. Early visits often have a tentative quality because the visitor and the mother are uncertain what to expect of each other. Though the lay worker stands much closer to the mother than any professional service provider, she and mother are not "equals." As one supervisor put it:

> "Once a community woman has been selected as a home visitor, the community tends to view her differently. No longer is she thought of as a relative of someone who lives down the street, but rather as a contributing, upwardly mobile person."(Newell, 1987, p.118).

That subtle difference in status can make interactions awkward. If, however, the lay worker can be both relaxed and respectful, her visits can be comfortable for both parties while remaining "special events."

Striking a balance interpersonally

Home visitors balance precariously on a series of tightropes as they try to create a useful, acceptable role with each family they visit. The lay workers must be assertive enough to approach strangers in order to recruit them into the program and confident enough to direct the attention of the mothers they visit to the program's agenda. Yet if assertiveness becomes didactic, domineering, or judgmental, the mothers will quickly lose interest in participating in the visits.

Even when rapport is established, each home visit can be marked by a tension between support and education, as the visitor balances her responsiveness to family interests and needs with a goal-oriented awareness of the agenda she wants to cover. Unless monitored, some visitors spend very little time on the curriculum, focusing instead on family needs or the personal concerns of the mothers. In the words of a supervisor: "It's very easy to be seduced into talking about all the mother's problems and never really give her anything back in terms of new information about child development." Yet single-minded emphasis on educational goals can invite problems of a different sort if the visitor does not embed her advice in the supportive give-and-take of a trusting relationship. One home visitor put it this way: "In order to help people, you've got to be listened to, and if I turn you off, you haven't heard a word I've said anyway. We're just going through the motions."

The lay visitor's willingness to share her own personal experiences can be a powerful aid to forming a trusting personal relationship. But it is difficult to share at this level and still maintain the perspective required to see the most effective way to help. The over-identification between visitors and families caused problems in one case:

> "Often the home visitors' own personal problems were not dissimilar from the problems they were trying to solve for the families—and that was extremely difficult to handle... We want people to be compassionate and understanding, but not to the point that they become part of the problem."

Because home visiting work with families is not based on standard scripts but draws heavily on interpersonal exchanges, the demand for sensitivity and self-awareness is unending.

Straddling two cultures

In many situations, the lay home visitor functions partly as a culture-broker, and that aspect of the work is fraught with ambiguity and tension. It is expected that lay workers will be respectful of the families served by the program, sensitive to cultural issues, and able to translate program messages into culturally-accepted terms. Their very closeness to that culture means, however, that many beliefs and practices are too deeply ingrained in their own life experiences to change easily. While the lay workers may respect the expertise that undergirds the program's recommendations, they only gradually become comfortable discussing ideas that fly in the face of traditions, and incorporating them in behavior is more difficult yet. As a result, individual lay workers often maintain "domains of silence," individual topics they avoid or address only tentatively, well beyond the period of preservice training (Halpern and Larner (b), in press).

Training inevitably alters the "layness" of lay workers, and some observers have warned that paraprofessionals can be "co-opted" by the professionals who surround them, coming to adopt a sterotypic agency-based view of family needs and problems rather than helping reshape the program to fit community values and concerns (Gartner, 1979; Powell, 1982). Some programs have fought this tendency by deliberately involving home visitors in ongoing adaptations of the program's curriculum, materials, and approach. Nevertheless, it can be difficult to train lay workers to convey the program's agenda without sacrificing some of their identification with the families they are serving.

Struggling to achieve personal goals

A final tension may arise between the lay worker's perspective on the future and that of the program that employs her. Put briefly: the home visitor hopes to advance, and the program hopes to keep her. A near-universal characteristic of low-income communities served by these programs is the absence of employment opportunities, and even talented, resourceful women like those chosen to be lay workers are often handicapped in the local job market by a lack of education and work experience.

The lay home visiting program can help local women enter the white-collar world of human service agencies, because it values the skills they already have and it offers a supportive way to build new ones. In the nurturing context provided by the supervisor and a team of peers, the personal growth of many lay workers is startling: one completes her high school equivalency exam, another learns to drive and buys a car, a third leaves an abusive husband and enrolls in the local community college. Advances tend to come in three broad and important areas: in education, in job-related skills and in confidence and self-esteem.

Unfortunately, many home visiting jobs are not linked to further opportunities within the agency or in the wider community. During the 1960s, the creation of paraprofessional positions served two purposes: their presence was intended to alter the culture of the agency, making it more sensitive to the needs and values of the people being served; and the positions themselves were depicted as "new careers" that created ladders of employment by which community members could climb out of poverty (Austin, 1978; Pearl and Riessman, 1965). Some of the current generation of lay helper programs seem to have lost sight of those former ambitions: many administators do not solicit the views of lay workers

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about agency policies, and they seldom plan opportunities for advancement within the agency. To continue their personal growth (and earn a more acceptable living), lay workers often seek other jobs, leaving the program, their supervisor, and the families in their caseload behind.

Staff turnover is stressful, both for the program that must train new workers, for the lay worker confronted by the new demands of a different job, and for the families who are asked to form a relationship with a new home visitor. Even this unplanned and wasteful process can benefit the larger community, however. The lay home visiting program's efforts to identify, nurture, and develop the skills of talented local women often launches them toward careers in human service or community leadership (Clinton and Larner, in press), enabling them to contribute in new ways to the well-being of their community.

The challenges ahead

It sometimes appears to these authors that we put too much on the shoulders of lay home visitors. It is crucial that we continue to clarify appropriate roles, expectations and tasks for lay home visitors, taking into account their characteristics as helpers, as well as the nature of the problems facing the families they serve.

Yet there is a further danger—that too much may be expected of parent support and education generally as a vehicle for altering the likely futures of poor children and parents. No single support strategy, whether interpersonal or financial, can address adequately the range of obstacles to healthy development that poor children and adults face. A variety of complementary strategies are needed. In that light, lay home visiting is an attractive element of a broader package of family support strategies we should all be promoting.

References

Austin, M. *Professionals and Paraprofessionals.* New York: Human Sciences Press, 1978.

Bond, J.T. and Halpern, R. The role of cross-project evaluation in the Child Survival/Fair Start Initiative. In H. Weiss and F. Jacobs (Eds.), *Evaluating Family Programs.* Norwood, NJ: Ablex, 1987.

Chamberlin, R. Conference exploring the use of home visits to improve the delivery of preventive services to mothers with young children. Evanston, IL: American Academy of Pediatrics, June, 1980.

Clinton, B. and Larner, M. Rural community women as leaders in health outreach. *Journal of Primary Prevention,* forthcoming.

Cochran, M. and Woolever, F. Beyond the deficit model: The empowerment of parents with information and informal supports. In I. Sigel and L. Laosa, *Changing Families.* New York: Plenum Press, 1983.

Davoren, E. The profession of social work and the protection of children. In E. Newberger (Ed.), *Child Abuse.* Boston, MA: Little, Brown and Co., 1982.

Dawson, P., Robinson, J., and Johnson, C. Informal social support as an intervention, *Zero to Three,* 1982, *3*(2), 1-5.

Gartner, A. The effectiveness of paraprofessionals in service delivery. In S. Alley, J. Blanton, and R. Feldman (Eds). *Paraprofessionals in Mental Health.* New York: Human Sciences Press, 1979.

Greenspan, S. and Wieder, S. Dimensions and levels of the therapeutic process. *Psychotherapy,* 1984 *21*(1), 5-23.

Gottlieb, B.*Social support strategies: Guidelines for mental health practice.* Beverly Hills, CA: Sage Publications, 1983.

Halpern, R. Home-based early intervention: Dimensions of current practice. *Child Welfare,* 1986, 63(4), 387-398.

Halpern, R. and Larner, M. The design of family support programs in highrisk communities: Lessons from the Child Survival/Fair Start Initiative. In D. Powell (Ed.), *Parent support and education: Consequences for children and families.* Norwood, NJ: Ablex, in press.

Halpern, R. and Larner, M. Lay family support during pregnancy and infancy: the Child Survival/Fair Start Initiatives. *Infant Mental Health Journal,* in press.

Hewett, K. *Partners with parents: The Home Start experience with preschoolers and their families.* Office of Human Development Services. DHEW Publication No. 78-31106. Washington, D.C.: U.S. Department of Health, and Welfare, 1978.

Lyons-Ruth, K., Botein, S., and Grunebaum, H. Reaching the hard-to-reach: Serving isolated and depressed mothers with infants in the community. In B. Cohler and J. Musick (Eds.), *Intervention with psychiatrically disturbed parents and their young children.* San Francisco, CA: Jossey-Bass, Inc., 1984.

Melosh, B. *The physician's hand: Work culture and conflict in American nursing.* Philadelphia, PA: Temple University Press, 1982.

Newell, W. *Supervisor's guide to home visitation programs.* West Alabama Health Services. Eutaw, AL, 1987.

Pearl, A. and Riessman, F. *New careers for the poor.* New York: Free Press, 1965.

Powell, D. From child to parent: Changing conceptions of early childhood intervention. *Annals of the American Academy of Political and Social Science.* 1982, 416, 135-144.

Travers, J., Nauta, M.J., and Irwin, N. The effects of a social program Final report of the Child and Family Resource Program's infant toddler component. Cambridge, MA: Abt Associates, Inc., 1982.

Zigler, E., Weiss, H., and Kagan, S. *Programs to strengthen families.* New Haven, CT: Bush Center in Child Development and Social Policy, 1983.

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Home Based Intervention: Catalyst and Challenge to the Therapeutic Relationship

by

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The Community Infant Project (CIP) began serving infants and parents of Boulder County, Colorado in February 1984. Home visitation is an important aspect of the project, comprising two-thirds of all client contacts. The decision to incorporate home visitation as the primary intervention approach was based on the need to reach a specific population of parents and infants. For example, one important function of the project is to identify and serve families who cannot easily make use of traditional, center based resources. In fact, most families at risk for child abuse and neglect experience difficulty in soliciting and using supports outside the family. In describing the significant proportion of abusive parents who themselves experienced abuse and neglect as children, Steele (1980) points out that "it is not surprising that as a result of these experiences in childhood, we see adults who are somewhat socially isolated and have a great deal of difficulty in reaching out to others for help and assistance" (p.57).

Our program also recognized the relative lack of mobility experienced by many new mothers in late pregnancy and in the first 3-4 months post-delivery. "Packing up" a newborn to be carried about outside the home (not to mention additional young siblings) can be a real production, and can involve a certain degree of risk and worry, especially in inclement weather. Many families served by our program cannot afford to hire a sitter more than occasionally. Also, many women naturally experience a desire to stay close to home with their infant during the first few months postpartum as they are getting to know their infant and her unique rhythms and personality. New mothers also experience a need for greater nurturance and sense of security for themselves during this relatively vulnerable period as they adapt and recover, both physically and emotionally, from the birth experience. Thus, for many reasons, the time surrounding the birth of an infant can be a difficult period for any new mother. These restrictions on mobility are exacerbated for mothers who do not have significant financial and emotional support.

In the three years since our program was launched, we have had the opportunity to experience both the benefits and the challenges to the therapeutic relationship of home-based intervention. The pioneering work of Ruth and Henry Kempe (1980), the San Francisco Infant-Parent Program (Pawl, 1987), and the psychoanalytic framework of Dr. Selma Fraiberg and her colleagues as described in their pioneering work, *Clinical Studies in Infant Mental Health* (1980), have been the models most influential in shaping our understanding of, and treatment approach to, families at risk for abuse, neglect, failure to thrive, and other types of parent-infant dysfunction. In coordination with other professionals from Boulder County Social Services and Public Health we strive to create an individualized treatment approach for each CIP family within which the emotional and material support of the parent(s), coupled with psychotherapeutic efforts to promote parental self-esteem, efficacy, and insight, will lead to enhanced capacity to enjoy and care for the infant. Development of a supportive and trusting alliance between therapist and family is critical to the success of this work. In this article, we describe several ways in which the attempt to establish a therapeutic alliance with parents and infants in their own home represents both catalyst and challenge to effective psychotherapeutic intervention.

Home visitors: welcome or intrusive?

Many writers and researchers in the field of home-based intervention have remarked upon the opportunity for practitioners to gain greater understanding of their clients' entire psycho-cultural milieu when they are permitted to observe and interact with them in their own homes and neighborhoods. When an infant at risk for abuse or neglect is the primary focus of therapeutic intervention, access to the home environment becomes crucial for other reasons as well. Intervention to stabilize or protect an infant must often occur quickly. Because the infant cannot verbally describe his needs or hurts, nor help himself without adult assistance, the therapist's ability to conceptualize the world as the infant is experiencing it is crucial in providing fast and appropriate intervention. Thus, assessment of the infant's actual living situation (in contrast to hospital evaluation alone) can permit the most pertinent interventions to be recognized and administered quickly.

> *We strive to create an individualized treatment approach for each family in our program. Development of a supportive and trusting alliance between therapist and family is critical to the success of this work.*

But how are home visitation and intervention viewed by the infant's parents and other family members? It has been our experience that although it is difficult to predict whether a family will find the initial home-based meeting comfortable (and even desirable) rather than intrusive and possibly degrading, the therapist must be aware that strong feelings of some sort will be aroused by his or her presence in the home. Whether these feelings enhance or inhibit development of a therapeutic alliance, the therapist must be alert to the family's feelings and be prepared to address them at the right time.

The case of baby Cindy highlights the value of the home enviroment for accurate diagnosis and appropriate intervention, and also illustrates the prompt results possible when parents respond positively and eagerly to the therapist's presence and treatment ministrations in their home.

Cindy was 5 weeks old when her parents, Sharon (36) and John (25), brought her into a local health clinic for treatment of diaper rash. Routine examination showed that Cindy had dropped to 6 pounds from her 7-pound birth weight, had almost no subcutaneous fat, and had fallen from the 50th percentile for weight to below the 5th percentile. Both parents appeared surprised and quite worried by this news, and were eager to cooperate with clinic staff to help Cindy. Cindy had been breast-fed exclusively to this point, and the clinic staff suggested that her parents also initiate supplementary formula feeding according to their instructions.

Throughout the following 2 weeks Cindy stopped losing weight, but her average gain of 1/2 gram per day remained below the "catch-up" rate targeted by the clinic. Staff worried that, although cooperative, Cindy's parents were not fully appreciative of the seriousness of Cindy's failure to thrive, and that Sharon might be having difficulty judging the passage of time between feedings. The family was referred to CIP for a thorough home and feeding assessment. Sharon and John welcomed the CIP therapist into their home. They stated that although they had liked the clinic staff, the clinic evironment had made them feel watched and criticized. John commented that he felt more relaxed "on his own ground." The parents also told the therapist how difficult it had been for them to remember feeding instructions and techniques learned at the clinic once they were back at home with Cindy. The parents had not expressed this difficulty to the clinic staff, and they did not appear to connect their uncertainty about the clinic's instructions with Cindy's continued weight loss. The therapist was able to develop a more helpful system for Sharon and John, using written instructions and rehearsal with Cindy herself.

Observation of this family at the first home visit revealed a mother who seemed unable to interpret her baby's cues or perceive her signals of distress. To the therapist, Cindy seemed quite thin, with a gaunt and hollow appearance, and a clear look of sadness about her eyes. It was at this point that the CIP therapist, who had considerable experience with the clinical use of videotaping to assess parent-infant interaction and to promote insight and feedback with parents of FTT infants, decided that Sharon and John might also be good candidates to this approach.

It has been our experience that some families are quite enthusiastic about videotaping and are excited about receiving a copy of the tape. Other families are fearful of how it might be used, and may not see it as a helpful tool, but as an opportunity for the therapist to control or even humiliate them. Thus it is critical that videotaping be used with the same degree of clinical sensitivity and experience that would be warranted for any other intervention technique. Ideally, the therapist should be prepared to recognize and work with the diversity of feelings that are likely to surface for a family as they have the opportunity to see themselves as others might see them, perhaps for the first time.

Although it is difficult to predict whether a family will find the initial home-based meeting comfortable (and even desirable) rather than intrusive and possibly degrading, strong feelings of some sort will be aroused by the therapist's presence in the home.

Fortunately, Sharon and John were very interested to have the therapist bring the videotaping equipment to their home. As Sharon brought Cindy out from the bedroom after her midday nap, Cindy nestled into her arms, rooting in a rather dramatic fashion. To the therapist, Cindy seemed quite hungry. The therapist asked Sharon if she thought Cindy looked like she might be hungry. Sharon was emphatic: "Oh no, not to me she doesn't. It's only been a short time since her last feeding." In fact, as the therapist was able to reconstruct from the family's schedule that morning, it had been nearly three hours. Cindy was then transferred to her father, who commented that he thought she might really be hungry. Sharon acquiesced somewhat reluctantly and went to prepare the formula. Cindy took the bottle eagerly and quickly. Her mother commented, "Well I guess she was a bit hungry."

Videotaping, and joint review of the videotapes by Sharon, John, and the CIP therapist, continued across the next 7 to 10 days. The parents' reactions to the tapes were dramatic. "My gosh, look how sad she looks; I can't believe it," Sharon exclaimed. "She is really trying to tell me how hungry she is." Sharon and John were both visibly shaken as they watched their baby on tape. It was as if some crucial empathic link to Cindy had suddenly become available to them. Nonetheless, the videotape also evoked strong feelings of embarrassment for both parents. These feelings were addressed openly by the therapist, who used this as an opportunity to empathize with their difficulty in gaining a new perspective on Cindy and on their relationship with her.

In the days and weeks to follow, the therapist continued to work closely with the family around the videotaping. The tapes continued to be helpful to Sharon and John in learning to read Cindy's hunger and distress cues, and served as a concrete way of observing Cindy's continued gains, both physically and socially. The parents were able to recognize and take pride in the increasing reciprocity between themselves and their baby daughter as documented by the videotaping. In addition, these parents were capable of considerable independent self-observation and self-correction once given an appropriate "distancing" tool such as the videotaping. In this way, videotaping can allow the family to recognize and implement their own strategies for change, with the additional advantage of preserving an important measure of self-esteem and self-efficacy while minimizing reliance upon an external authority figure, such as the therapist. Sharon asserted that she could now see when Cindy was hungry, and she reflected that perhaps she had just been "too close to be able to see what was happening." Within four weeks, Cindy had risen to the 10th percentile for weight, and the 25th percentile for height/weight ratio.

In contrast, many families do not view a home visitor with the kind of initial enthusiasm, trust, and appreciation expressed by Cindy's parents, even when they are unwilling or unable to take advantage of center-based resources. Refusal or inability to acknowledge a need for assistance (or the very existence of a problem) is just one of many factors that can play a part in making it difficult to initiate a therapeutic alliance with such families. Whatever the particular circumstances and dynamics contributing to a family's resistance to engagement with a therapist, it is vital that the therapist come to respect and, if possible, to understand this resistance.

Ms. Martinez was a young, single mother of a toddler and a 6-week-old infant, all living in a tiny and impoverished 2-room apartment. For a short time before the birth of this second child, Ms. Martinez had been coming for prenatal visits to nearby family clinic. For reasons not clear to the clinic staff, she began to miss appointments and eventually stopped coming altogether. The case was then referred to the CIP program. The CIP therapist, who was not from the Hispanic community, was introduced to Ms. Martinez by a young Hispanic woman who had become acquainted with Ms. Martinez through the family clinic.

The CIP therapist's initial visits with Ms. Martinez took place through the partially opened screen door, as the therapist remained outside on the front step. Across many such visits with her, the therapist was to come to understand something of the psychological meaning for this young woman of this simple, physical boundary represented by the door. Many aspects of "boundary"—both physical and psychological—had been violated in Ms. Martinez' childhood. In particular, the therapist was to learn that Ms. Martinez had been sexually abused repeatedly by two maternal uncles across a seven year period of her childhood. Her mother had been aware of the abuse, but had not protected her young daughter from these uncles. These violations remained a source of obvious pain and sensitivity for her. As a young mother, Ms. Martinez had found an important source of security within the boundaries of her small home, and these could not easily be shared.

The therapist was able to sense the importance of these conditions imposed upon their earliest meetings, and chose to respect, not challenge, them. Gradually, Ms. Martinez was able to allow the therapist to come into the apartment, though both of them remained standing throughout the entire visit. Eventually, after a number of such visits, the therapist was invited to sit down. Ms. Martinez and her therapist were to accomplish many things throughout the course of a fairly secure and enduring alliance. She and her children began to attend the family clinic for medical checkups once again, and she was able to take advantage of the resources of a number of other county agencies which had seemed thoroughly confusing and inaccessible to her before. Through her relationship with the CIP therapist, Ms. Martinez began, cautiously and slowly, to allow other people to make contact with her. The creation of such an alliance must be seen as the result of a delicate balance between persistence and sensitivity on the part of the home visitor, who would not likely have succeeded if she had insisted upon some set of inflexible or institutionally-derived "rules" for the establishment of this therapeutic relationship.

The home setting: stimulus or hindrance to therapist empathy?

Greater appreciation for the daily environment of family and infant can promote enhanced empathy on the part of the therapist. In contrast to an institutional setting, the home offers a multitude of additional cues (received at both conscious and unconscious levels) which can be noted and used to forge important relational links between therapist and adult or infant client. The home setting has the potential for accelerating and strengthening the therapeutic alliance with unmotivated or resistant clients in particular, often in creative and unexpected ways. On the other hand, meeting on the family's "turf" can become confusing and inhibiting for both parties if the therapist becomes

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A therapist on the family's "turf" may become overwhelmed by the sheer amount or distressing character of the information available. It may also be difficult to accept limitations on interaction or to feel in the position of "selling" oneself to clients.

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overwhelmed by the sheer amount or distressing character of the information available. Therapists may also find it difficult to accept what seem to be odd or unreasonable limitations imposed on their interaction while in the home.

Mildred (25) was referred to CIP during the third trimester of her pregnancy. She had had 3 miscarriages in the past 4 years, and was only able to carry this fourth pregnancy to term due to surgical intervention by her obstetrician. At the time of referral she had no contact with the baby's father, and was living with her own mother in a remote mountain home. Mildred's family history, as well as her own, suggested a high risk for parent-infant dysfunction. She had been seen at the Mental Health Center at 9 years of age for school truancy, visual-perceptual and gross motor disturbances, and impaired peer relationships. Mildred's father had been diagnosed as paranoid schizophrenic, and had been in hospitals for most of Mildred's childhood. Her mother also received sporadic treatment for psychiatric difficulties from 1969 to 1976. Mildred reported her childhood as "severe," remembering that both parents had wished she were a boy (in fact she was given a boy's name). Mildred's mother had described her pregnancy with Mildred as "horrible," and associated the pregnancy with the breakdown of her marital relationship.

At the time of referral, Mildred's mother had not been out of the house for several years, and Mildred felt compelled to live at home until she could find "someplace to go." Though unwilling to present herself at the Mental Health Center, Mildred had accepted her WIC (county nutritional program) nurse's recommendation that "someone like a nurse" visit her at home. Mildred "grilled" the CIP therapist who came to visit her, wanting to know who she was, where she was from, and why she was there. Eventually, she agreed to "allow" the therapist to continue to visit her, making it quite clear that she would accept no involvement with any mental health center.

Dorothea Lange, FSA, 1939 Library of Congress

Mildred also informed her therapist that she would only be allowed to come to ther house until the baby was born, since Mildred's mother had insisted that there be no visitors for the first 3 months of the baby's life. Shortly thereafter, several other of the mother's prohibitions come to light as the multigenerational pattern of isolation, suspiciousness, and paranoia were increasingly stimulated by the "threat" of this visitor from "the outside." After the birth of Mildred's baby, Mildred's mother instructed visitors to wear a surgical mask while in their home; she instructed Mildred to sew up the arm holes of the baby's sleeper so that the baby could not scratch her face and hurt herself; and she insisted that as little light or sound as possible be allowed to penetrate into the house during the baby's first few months at home. Mildred appeared to accept these prohibitions as her own, but appeared passive, depressed, and ineffectual in relaying them. Throughout the therapist's first few visits to their home, Mildred's mother never came out of her room to greet or acknowledge the therapist. Nonetheless, she continued to be a very real, but invisible, presence in the therapist's interactions with Mildred.

The therapist began to search for ways to connect directly with the mother. During the fourth visit, Mildred's mother walked through the room, and allowed herself to be introduced to the therapist. Gradually, their conversations and interactions increased. Eventually, the therapist was given permission by Mildred's mother to visit Mildred in the hospital and "allowed" to come to the home after the baby's birth.

Another key breakthrough in the therapist's efforts to understand this family's unique psychosocial history came soon thereafter. As with Mildred's own mother before her, Mildred reported to the therapist that she wanted this baby to be a boy; she had a girl. Once again, in an uncanny mirroring of her mother's solution to this "problem," Mildred gave her daughter a masculine name. For some time, the therapist had had no solid clues linking her intuitions about Mildred and her mother to this generational repetition of history. As the therapist strugggled for ways to uncover the "ghosts in the nursery" for this newest family member, Mildred's mother brought out the family photo album at one of their visits. As Mildred, her mother, and the therapist pored over the photo album together, the therapist was able to gain important information and insight into the lives of these two women within the context of their family's unique history and patterns of interaction (particularly with regard to childrearing beliefs and practices). Such informal disclosure—in contrast to the more direct, and heretofore fruitless, questioning by the CIP therapist—proved to be the creative intervention the therapist had been waiting for, and one that would have not occurred as soon, if at all, had Mildred been coming alone to see the therapist at her office.

Mildred's initially resistant and suspicious response to the therapist underscores the difficulty for therapists in maintaining a warm and empathic stance in the face of such a "welcome." Therapists who have trained for years in their profession and feel justifiably enthusiastic and proud of the skills and services they have to offer can find it difficult and discouraging to be put in the position of "selling" themselves to clients who seem unappreciative and uninterested. Such feelings need to be acknowledged and worked through in order to persevere in serving the other very real, but "silent," client in this picture—the infant at risk.

Balancing empathy and objectivity: the role of supervision

For the therapist meeting with clients in their own homes, the encounter is unbuffered, both physically and emotionally, by the standardizing and familiar uniformity of an institutional setting. While this situation can serve to hasten and enhance the therapist's appreciation for the "whole client," the physical and emotional character of a family's living space also has the power to evoke strong psychological and philosophical responses from the visiting therapist which can feel quite unmanageable at times. To cope with the occasionally overwhelming amount and nature of the information revealed in the home visit, the therapist may find herself "filtering the data"—making immediate use of some of it, while "storing" or "ignoring" other bits until they can be dealt with objectively and competently.

Frequent and sensitive supervision of all home visitors is crucial to maintaining therapist morale and professional competence. The supervisor can help the therapist to maintain empathy for the client as well as objectivity.

Our experience in the Community Infant Project is that frequent and sensitive supervision of all home visitors is crucial to maintaining therapist morale and professional competence. In the same way the the CIP therapist aims to provide a nurturing and reliable "holding environment" for the parent (enabling and empowering the parent to begin to provide similar nurturance for the infant), so the clinical supervisor can act as an "auxiliary ego" and observer for the therapist, helping him or her to maintain empathy for the client as well as objectivity with respect to critical, emotionally powerful "facts" about the client's situation. The following case illustrates this point.

Sally reported to her CIP therapist that a male friend of hers had begun helping her to care for her children. He seemed to have time and money and no particular place to spend either, and thus he was able to provide both financial assistance and respite from child care to this needy and grateful young mother. In the presence of this embattled mother, however, the therapist did not immediately "hear" additional information from her that this man in fact had a long history of child molestation. The therapist found herself to be so "in tune" with Sally's joy and relief at finding a caring neighbor that she could help neither herself nor Sally confront this important piece of information right away. Later, within the "safe" and distanced context of a supervision meeting, the therapist was able to "come back" to this information and create a plan to address it empathically, but directly, with Sally.

Initially, the therapist worried that this inability to process the information right away might reflect some broader countertransference reaction to the mother which could also blind the therapist to any number of other important facts about the family's situation. Was she then incompetent to work with this particular family? In addition, the therapist feared that her lack of immediate response to the mother's information about her male friend might be interpreted by the young mother as tacit endorsement of her arrangement. Would the mother be confused or angered by the therapist's later "challenge" to her plans? What sort of crisis might this pose for their relationship? Sensitive and experienced supervision assisted the CIP therapist in disentangling these many issues. The supervisor was able to bolster the therapist's self esteem in confronting a challenging, and emotion-laden situation (that is, the posibility of eventual sexual abuse of the client's children should her arrangement with, and trust in, this man continue) while helping her to conceptualize possible reasons for its occurrence, and to formulate specific strategies to correct it.

It has been our intention to address only a few of the many benefits and challenges to the therapeutic relationship that working with parents and infants in their homes can provide. Ahead of us all lies the difficult and challenging task of continued identification and validation of the precise nature and structure of this type of intervention. We look forward to continued dialogue and interchange with our colleagues in the field as we pursue these ambitious goals for the sake of our parent and infant clients.

References

Fraiberg, S. *Clinical Studies in Infant Mental Health: The First Year of Life.* Basic Books, Inc., 1980.

Kempe, C.H. and Helfer, R.E. (Eds.). *The Battered Child. Third Edition.* Chicago: University of Chicago Press, 1980.

Pawl, J. Infant mental health and child abuse and neglect: reflections from an infant mental health practitioner.*Zero to Three,* 1987, 7 (4) pp. 1-9.

Steele, B.F. Psychodynamic factors in child abuse. In C.H. Kempe and R.E. Helfer (Eds.), *The Battered Child. Third Edition.* Chicago: University of Chicago Press, pp. 49-85, 1980.

The Post-Partum Support Project: Serving Young Mothers and Older Women through Home Visiting

by
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Using foster grandparents as regular home visitors and companions to overwhelmed, isolated mothers with new babies can be a way of providing support to two populations: young women and their infants, at risk for child abuse and neglect, and older women, often isolated themselves because of widowhood or divorce.

The Post-Partum Support Project (PPSP), a research and demonstration project supported by the National Center on Child Abuse and Neglect, included regular home visits by foster grandparents, a mothers' support group and social work services in a comprehensive short-term preventive intervention program. The goal of the intervention was to stabilize these families so that at the end of six months they would be able to function effectively without the foster grandparent or be referred to an ongoing treatment program.

Mothers with infants less than six months of age were eligible to participate in the project if they felt they needed help and if they had poor or non-existent support systems. They were approached by project recruiters in the waiting areas of Presbyterian Hospital's pediatric clinic or referred by social workers or pediatricians. The mothers readily accepted the offer of home visiting by an older person, but would not necessarily have sought help. Many were found to be actively abused by their spouses and in financial difficulties threatening their supply of food and shelter. The birth of a new child presented a crisis, and an urgent need for support and assistance.

The foster grandparents, who represented both our cadre of home visitors and the project's second target population, were part of the New York City Foster Grandparent Program, which is federally funded through ACTION. They were women at least 60 years of age who met the federal goverment's low income eligibility criteria for participation in stipended programs. Like the young mothers, the foster grandparents were black or Hispanic; most were divorced or widowed. With a lifetime of experience and wisdom to offer, the foster grandparents found that the project not only gave them an opportunity to play a meaningful role with a new generation but also a chance to find support among other women of their own age.

Components of the program

The first component of the program, *home visiting*, involved in-home placement of foster grandparents. The foster grandparent came to the home of a young mother and her children two days each week for four hours each time. Young mothers who expressed interest in the program to a recruiter were screened for eligibility. A home visit by the project social worker and research psychologist was used to make sure that the house and neighborhood were safe for an older person to visit regularly. Following the home visit, young women were matched with a foster grandparent from the pool of trained older women. Criteria used in pairing mothers and foster grandparents included ethnic group, personality, accessibility by public transportation, and activity level of the family in relation to the foster grandparent's physical condition. The next step was a visit to the young mother by the chosen foster grandparent and the social worker. If both mother and foster grandparent felt the match was appropriate, they signed a letter of agreement, which made the mother's participation official. Each mother understood that the foster grandparent was not to be used as a babysitter, but would be coming to the home two days a week to provide company and help in managing the demands of children and household.

In the second component of the project, *the biweekly mothers' support group*, the mothers of the project met with the social worker and discussed topics of mutual concern. At these meetings, which included infants, the mothers were provided with information, peer support, and an opportunity to express concerns and frustrations about their children and significant others. The third component of the program consisted of *social work counseling* and *help with concrete services* as needed.

What did the foster grandparents actually do?

Each foster grandparent was assigned to two families at a time, visiting each twice a week for approximately 4 hours each visit. On the fifth day of the week, the foster grandparents had a group meeting at the hospital with program staff. The foster grandparents kept a daily log of each home visit. These logs served to alert project staff to serious problems in the household (e.g., no food,

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The Post-Partum Support Project was conducted jointly by The Presbyterian Hospital in the City of New York and the New York City Department for the Aging, with the support of a grant from the National Center on Child Abuse and Neglect (#90CA0935). The following staff were involved in the execution of the research and demonstration project. Principal Investigators: Nicholas Cunningham, M.D., Department of Pediatrics, Columbia University College of Physicians and Surgeons; Mary Mayer, New York City Department for the Aging; Marcia Voge, New York City Department for the Aging. Project Director & Research Psychologist: Elizabeth Anisfeld, Ph.D., Department of Pediatrics, Columbia University College of Physicians & Surgeons. Project Social Worker: Madeline Pincus, M.S.S.W., Columbia Presbyterian Medical Center, Foster Grandparent Coordinator: Miriam Fox, M.S.W., New York City Department for the Aging.

The Post-Partum Support Program is currently continuing as a service program funded jointly by New York City/Human Resources Administration and Presbyterian Hospital. The program of in-home placements is being expanded to other hospitals with a grant from Chase Manhattan Bank.

no heat, illness) and were later used as a source of information as to what the foster grandparents actually did on their home visits.

The daily activities of the foster grandparents included bathing, dressing and feeding the infant; playing with an older child; helping the mother plan meals; babysitting while the mother ran short errands; and watching TV with the mother. On some days, the foster grandparent would help the mother get herself and the children organized and out of the house in time to arrive at an appointment (welfare, medical, mothers' group). Throughout all these daily activities the foster grandparent was demonstrating for the mother how to nurture her children.

In addition to routine activities, the foster grandparents also become engaged in some long range activities that resulted in concrete accomplishments. For example, one foster grandparent successfully advocated for window bars (for child safety), another for improved housing (by taking pictures to court) and a third for removal of peeling lead paint. Several foster grandparents gave their mother support in negotiating the public assistance system.

Far more important than the concrete help provided was the relationship that developed between the foster grandparent and the mother. The character of the relationship between the foster grandparent and the mother ranged from simulating a natural close mother/daughter relationship to being fairly distant, but with the mother's recognition that the foster grandparent was necessary for the child's care and well-being. The type of involvement of the foster grandparent in the family structure varied. In some households, the foster grandparent was more directly involved with the mother, in some with the children, and in others there was a blending of these two. Very often the foster grandparent became most involved with the child in the family at highest risk. Because of her own need to find a niche in a strange household, the older woman often gravitated toward the child who received the least attention—the easily ignored, outcast or scapegoated child. In some cases, this was the infant, if he or she were too quiet or too irritable. Often it was a sibling, typically a toddler who was labelled a "behavior problem" or "hyperactive" by the overburdened parent. These children frequently became manageable, more sociable and even more attractive through the attention of the foster grandparent, and consequently more appealing to the mother.

What did the mothers find most helpful?

In most cases, the mothers identified the foster grandparent as a source of emotional support and a respite from loneliness. In fact, in termination interviews, mothers identified "moral support" as the most important benefit from their relationship with the foster grandparent. In declining order of importance were "sharing knowledge of child care," "sharing wisdom," "helping mother get organized," and "help with physical care of the infant." The foster grandparent also gave mothers a chance to attend to such basic needs as taking a shower and buying groceries. (At least 25% of mothers admitted to leaving their children home alone before entering the program.)

What training and ongoing support do foster grandparents need?

A two-week orientation and training program was developed to ease the entry of the foster grandparents into their new, home-visiting role. Topics in the training included how to engage depressed/resistant mothers, and how to deal with awkward situations involving other family members. Role playing and other experiential exercises were used to heighten empathy and tolerance, and to enhance helping skills.

In addition to the initial training, the foster grandparents attended a weekly group meeting at the hospital, at which they discussed any problems they were having with their families. This was augmented by individual counseling as needed. The weekly meetings provided an opportunity for project staff to offer support to the foster grandparents and to monitor what was going on in the homes. Many of the families had overwhelming problems and staff had to be vigilant in guarding against overinvolvement on the part of the foster grandparents. The staff was sensitive to enhancing the self-esteem of the foster grandparents and encouraging their own good judgment. A common staff saying was that "We nurture the foster grandparents so that they can nurture the mothers, who can then nurture their infants." Even though foster grandparents have to be quite independent in order to work alone in clients' homes, support by a strong, professional staff is critical in such a program.

Preventive intervention and a bridge to other services

While the young mothers in our program did make use of the pediatric clinic of our urban hospital, they often were unconnected to other professional services or to informal sources of emotional and concrete support. For many of the mothers the birth of an infant threatened to make a precarious situation untenable. Other mothers had been unwilling or unable to acknowledge longstanding family problems before participating in the program. As the following case vignettes illustrate, foster grandparents not only help young mothers to mobilize their own resources but also serve as a bridge between isolated families and agency supports. Coming into the homes of young mothers to help with a new baby, foster grandparents are much less threatening than professionals. Once mothers learn to trust the foster grandparents, they may be willing to seek professional help as needed.

Veronica

When we first met Veronica she was 27 years old and had a 4-year old son, Sean, and a 2-month-old daughter, Amanda, who had been born 6 weeks

Subjects and Predicates

prematurely. She and her children were living in a crowded, overheated one-room apartment in one of the worst neighborhoods in Harlem. Veronica's husband had recently been arrested in a drug raid and was in jail.

Until Amanda's birth, Veronica had been working full time as a claims investigator for an insurance company and Sean had been in day care. Because Amanda was born prematurely, she required a great deal of attention. Veronica did not want to return to work until she felt sure that Amanda was strong enough to be left in day care. Meanwhile, Veronica's unemployment insurance was running out and she was not yet receiving welfare checks (she found the welfare system demeaning and was distressed that she had to accept welfare, even temporarily). The rent had not been paid for several months. Shortly after we met Veronica, eviction authorities arrived at her door with papers in hand, ready to dump Veronica's meager possessions out onto the street and to padlock the door. Fortunately, a Visiting Nurse who happened to be in the apartment physically blocked the door and thwarted the eviction procedure.

But for an aunt to whom she could talk and who would occasionally take care of Amanda, Veronica was alone. Her husband was in jail; she was estranged from her mother.

Fortunately, while waiting for an appointment in the Pediatric Clinic with Amanda, Veronica was approached by a recruiter from the the Post-Partum Support Project. After she expressed interest and was screened for the program, she was matched with Ellen, a 65-year-old divorced black woman, also from Harlem. Once Veronica and Ellen signed the program's letter of agreement, Ellen began coming to Veronica's apartment twice a week for four hours each day. Ellen helped to feed and care for Amanda, played with Sean and listened and talked to Veronica. The two women soon became good friends. Ellen, who initially had had some rather negative prejudices concerning young mothers, came quickly to respect Veronica and to appreciate her strength in the face of adversity. Veronica, in turn, found that a relationship with someone who appreciated what a good job she was doing helped her to grow stonger.

In addition to visiting Veronica at home, Ellen helped her to get to medical and welfare appointments and to the program's mothers' group meetings. During 4 months in the program, Veronica was able gradually to get her life organized and to reach the point where she could return to work.

Sonia

After Sonia delivered her third baby, she was introduced to Juanita, a calm and sensitive 65-year-old foster grandmother. Sonia stated that she could not control her 3-year-old son Jose, who fought continuously with Hector, his 1-1/2-year old brother. Exhausted by caring for these two toddlers, Sonia did not know how she would manage the care of a new baby as well. Sonia told project staff that she had a good relationship with her husband, a taxi driver.

While participating in the program, Sonia suffered first a broken finger and later a black eye. She denied being battered, however, and said the injuries were the result of "accidents." Eventually, the foster grandmother was in the home during a fight which left Sonia unconscious. On his way out of the house, Sonia's husband implored Juanita, "Please help my wife." Juanita helped Sonia get medical care and a referral for counseling, which she was able to accept.

Juanita served as a receptive "grandmother" to 3-year-old Jose. One day he told her quietly, "No one knows how I'm going to kill myself." Juanita alerted the program social worker, who began to work with the family around this issue. The social worker learned that Sonia had heard Jose make similar statements many times, but, feeling that he was attempting to manipulate her, she had resentfully denied their significance. With considerable assistance, the family was able to become involved in a long-term therapeutic nursery program for Jose, which included therapy for the parents.

Conclusion

An intensive home visiting program can use non-professionals as part of a comprehensive intervention to help overwhelmed mothers with new infants. As mothers gain the strength to function on their own or to seek professional help, potentially negative consequences for all the children in the family are prevented. By creating a warm, supportive and tolerant relationship with a mother, the foster grandparent lessens parental stress, reduces the risk of abuse, and increases the mother's capacity to care appropriately for her children. In the process, the foster grandparent gains satisfaction and fulfillment from her role as a home visitor and companion for a younger woman in crisis.

A Psychoeducational Approach to Developmental Intervention

by

Ruth S. Pearce and Shelley Gallenson

As Child Development Specialists working with infants and their caregivers in the home, we have modeled our approach on that of Selma Fraiberg. Coming from the perspective of child development, however, we emphasize the unity of insight and education as central to the aim of modifying the relationship of parent and child. In fact, we hold that a division of labor in which the teachers "teach" and the therapists "interpret" is untenable and a disservice to infants and families.

Over the last five years we have been engaged in private home-visit consultation to middle and upper middle class families, and have become increasingly interested in the ways in which education contributes organically to the therapeutic process. Since affluent parents have more choices available to them and more power in exercising those choices, they are more likely to view themselves as collaborators in a mutual undertaking than inner city families. It may seem surprising that they express a strong need for developmental education and are thirsty for advice as well. Their very "empowerment" combined with such clear wishes has helped us to see the interweaving of education and self-exploration in the intervention process.

The following cases have been chosen to demonstrate "developmental intervention" in practice with a number of problems common to the first year of life. We hope to continue at a later date with cases from the second and third years.

I. The memory of a tragic loss disrupts the potential for attachment in a healthy mother.

Miriam, the mother of a three month old infant girl, was referred by her pediatrician because she seemed depressed and frightened, expressing deep worry that her baby would fail to thrive. She often called the doctor as many as five or six times a day, although whenever she visited the office, the infant was gaining weight and in all ways seemed well. At the first home visit Miriam spoke of the baby as "not blooming", said that she was whining a lot and had to be held constantly, and that if she continued to feel this depressed "couldn't the baby be autistic?" She seemed to be saying that her fear for her infant's survival could include a kind of psychological death as well.

After the first home visit Miriam and the CDS (Child Development Specialist) agreed that she would come to the home daily for at least a week so as to get to know the mother and baby. Each day they sat on a large rug while Renee lay on her tummy on a blanketbetween them. The CDS had ample time to talk with the mother and observe Renee through feedings and many other interactions. What the CDS observed was a mother who, in spite of her despairing mood, knew her baby well, was able to accommodate even to her way of nursing in an awkward position, and held her with care and warmth. And in spite of Miriam's suspicion of pathology at every turn, Renee smiled with pleasure whenever her mother came into sight.

As they talked Miriam began to tell the CDS about the pregnancy and her life prior to the birth of the baby. Like many mothers, she was approaching forty, in a profitable career, when she and her husband realized that they did not have much time left in which to decide to have a baby. Once decided, the pregnancy had been a healthy and sanguine one. It was only when she brought the baby home that she found herself helpless and scared. What she could not now comprehend in herself was the pervading premonition that something terrible would happen to this baby—that in some way she did not deserve to have her. Had she assumed that she could be a good mtoher? Yes, and in fact she felt that her own mother (who lived far away) had been a wonderful model for her. It was, in fact, this aspect of her history that made for a good prognosis and for a positive working transference with the CDS.

On the home visits when Renee began to whine, Miriam, whose tendency was to pick her up immediately, began to look at the CDS for cues. The CDS, by continuing the conversation, encouraged Miriam to delay her response, thereby permitting Miriam to witness the baby's capacity to appease herself, reach for objects, look about, smile, and even coo awhile before complaining in earnest. Once this became commonplace, Miriam began asking for help in other areas. How long could she let her cry? If she let her husband take care of Renee at night would that ruin the attachment to her? Renee cried whenever they were in the car—what should she do? The CDS answered the questions, recognizing that Miriam was coming to a formulation of her problem.

It was not until some weeks after the intervention began that Miriam told the CDS more about her family of origin and the event that had changed her life. She was the oldest of three children, two girls and a boy; she had been protective and loving with both siblings, especially with her sister, who became her dearest friend in adulthood. Three years earlier her sister had died suddenly from a cerebral aneurism, leaving Miriam devastated. "Until then I really believed that life would pretty much go my way."

The mourning had been long and agonizing, but the decision to have a child had brought it to an end. She was delighted that the baby was a girl and named her Renee after her sister. The deeply unconscious fear that she had marked her own child for death did not enter

her head until she related her story to the CDS. Then a flood of memories returned, including an obsessive thought that she could have saved her sister had she been there.

It was not long before Miriam recognized that she had a thriving infant; with the recognition she acknowledged her own competence as a mother, though her lurking fear for her daughter's survival was never to disappear altogether. The CDS remained her "reality tester" (or perhaps *in loco parentis*) whenever she felt she was being "overprotective" in the face of illness, injury, the death of a pet, or some other poignant reminder of mortality.

Miriam is a healthy intact mother who would have found a way out of her dilemma with time and without professional help. But the infant Renee might have suffered, and the mother's growing regret over lost time could have affected their relationship permanently. The salient aspects of the intervention were: 1) the forming of an attachment to the CDS, 2) the attention given to her own "over-protectiveness" and the accompanying effort, using the CDS's help, to pull back, allowing the anxiety to emerge; 3) and with it the many connections to her sister's death, most dramatic being her remembered thought that she might have been able to save her had she been there.

II. Marital discord and a mother's identity crisis threaten the development of tension regulation in her six month old baby.

Caroline was 6 months old when she and her mother, Jane, were referred to a CDS by the chief of pediatrics at the very hospital where Jane worked as a pediatric nurse. It was, for her, an appalling experience, "humbling to say the least," to feel that she could not "keep this baby happy."

"I don't understand it," she said. "The child won't let me go anywhere. If I leave the room she screams. If I stay she's fine for awhile but then she wants to be held all the time." Jane's need to objectify her child and her problem was part of an effort to find a way back to her normally confident and competent self. But it only barely concealed her anger—even the CDS was included in the bitter look that Jane cast at the world.

Jane was 35 when she met, married, and had Caroline. "I had my baby just under the wire, and it's the only one I'm going to ever have," she told the CDS on the telephone. Her husband already had two grown children and, although it was his "gift to his wife," he was none too happy to be starting a second family. From the beginning Jane had a template for motherhood; she knew how she was going to do it, and the CDS suspected that she had spent many an hour criticizing the mothers she had seen on the pediatric wards.

One thing that Jane had not banked on was that her husband also considered himself an authority on the subject of child rearing. He carried the banner of experience, declaring that "she has no idea what it's really like to take care of a baby." When Jane decided to let "the child" cry it out, her husband would not permit it. His practice was to dance wildly about with the baby in his arms, singing and bouncing. When Jane tried to stop him there was a shouting match. Between Jane's "system" of all-or-nothing and the father's panic, the baby was more than distracted, she was driven to distraction.

In the first home visit the mother and CDS sat in the living room with the baby on the floor playing fussily for more than half an hour while they talked. Caroline's irritability did not seem to bother Jane, whose need to talk took precedence over anything else and, surprisingly, the whining never escalated into a full blown "fit." All this while Jane was saying that she missed her career, felt cheated by fate and undermined by her husband.

Jane thought it was not normal for a baby to start crying whenever she left the room. The CDS suggested that they try it out then and there; she would stay in the room with the baby and Jane would leave. When Jane left, the baby did indeed cry. The CDS suggested that she call out to Caroline, just say anything to make auditory contact and stay out another half a minute. Jane's voice mollified Caroline a bit and Jane remained out another minute.

When she returned the CDS told her that her baby was developing a very solid attachment and that the crying, far from being an indication of Jane's failure as a mother, was clear evidence of her success. But Jane's anger and the distance she had created in order to control it would not permit her to feel any pleasure or pride. Parallel to the baby's need for stimulation was the mother's need for input. "You have to tell me what to do." She then got out a piece of paper and wrote as the CDS talked.

The recommendation was to do what had already been tried in the home visit: the CDS asked her if she thought she could try responding to her child as they had done together earlier. It would not be as systematic as what she might want (either letting her cry it out or holding her). She replied that she could, and the CDS said that if she found it too difficult to call her. "Should I keep a log?" she asked. "What a good idea," said the CDS.

Jane then asked for help with her husband. While the CDS recognized that his general level of excitment and inability to tolerate distress had added to the confusion and conflict, she also saw that Jane's tendency to distance and mechanize her relationship with her baby had understandably caused concern in her husband. She suggested that they meet together and see if they could come to some agreement.

The CDS met with the parents and described to them what she felt was the heart of the problem. She spoke briefly about the effect of the human infant's cry on parents, and that they were each trying to cope in their own ways with their baby's distress. She pointed out that the father's need was to console the baby, and that Jane's need was to give the baby firm predictability at all costs. For the father it had turned into a rescue operation from a "cold and ruthless mother"; for the mother it had turned into a war to retain her very rights as a mother. The CDS also said that they brought to this experience their own past experiences and models for coping, and suggested that they could use some marital counseling to identify the ways their baby was altering their relationship.

Jane continued to use the CDS for many months, and was able to be less rigid in her ways of handling Caroline's and her own frustrations. She was increasingly able to follow Caroline's cues and read the messages in her behavior. Her husband withdrew from his armed response, and with time was able to allow her more autonomy. But they did not go into conjoint therapy, and the competition between them remained just below the surface. Caroline is now two and a half, a self-reliant, enthusiastic, and social little girl. Over the next year the task of becoming part of a threesome, of coping with the complexities of the Oedipal phase are bound to be difficult. The parents may intutively recognize this and move to resolve their relationship.

Jane's need for structure to counter her anxiety and anger was only a little greater than her need for the CDS to be an ally against an encroaching husband. The CDS's willingness to provide this without taking sides enabled Jane to keep up with the developmental needs of her child, and may even have paved the way for more important internal change at a later date.

III. A traumatic separation at ten months transforms a secure attachment into an anxious-resistant one.

A family with an 11 month old boy was referred to the CDS with a severe sleep problem. He was waking ten or twelve times a night screaming for his pacifier. His mother was beside herself. What unfolded was a story of a severe separation trauma. A marital crisis at ten months had led to the mother's abrupt departure from the home for two weeks. At the same time the nanny, who had been with the baby since birth, also left. While the mother was gone, the father was left with the major caretaking responsibility. Faced with a crying child, he found himself unable to console the baby, became frightened and withdrew from physical contact with him. At that point the housekeeper, who was familiar but not close to the infant, took him to her home and kept him there for the duration of the mother's absence. Thus at the height of the development of a strong attachment to his mother and a secure trust in caregiving others, Max experienced a loss of everyone close to him, as well as a separation from the familiar surroundings of home.

When Max's mother returned her baby was a "different child." He would not look at her, rejected all overtures, and was subdued and sad in contrast to his earlier friendly and jovial nature. She reported that right after her return he had night terrors, which had now diminished to the present symptoms.

The task for the CDS was to enable this mother to actively reestablish her relationship with her child without the threat of a recurrence of loss for the child. It became clear by the second home visit that Debbie, the mother, wanted to make restitution to her child for the harm she felt she had done. But the process of wooing the baby to a trusting relationship would not be easy in the face of a demanding and at times angry baby. Together the CDS and the mother examined and discussed the problems that arose in terms of normal development and this baby's special circumstances.

Debbie's strong commitment to win her baby back was undermined by her interpretation of every protest as a reproach. When in the presence of the CDS these distortions were minimal, but on her own, she lost the capacity to differentiate. Discouraged and frustrated with the loneliness and slowness of change, Debbie then expressed a wish to bolt, and indeed her earlier abrupt departure was an extreme example of the way she commonly dealt with stress.

She had always depended greatly on a nanny to share in the responsibility of caregiving. The CDS then made the decision to recommend hiring another nanny, knowing that the mother would at first interpret this as failure. The process of allowing the mother to express her feelings of doubt, anger and defeat without quick reassurance was essential to Debbie's ability to make a free choice. Once acknowledging her conflict between the wish to escape, stirred by the underlying anger at the baby, and the wish to be the rescuer, she could begin to welcome the idea of help in her endeavor. The family began to reunite around the infant. When the mother became worn out the father was able to offer respite by moving in with the infant at night. The parents went into therapy to deal with their marriage. The CDS encouraged predictability of routine and environment, and the sleeping problem gradually abated. The attachment was less anxious and more secure with time. Under the stress of later events and developmental phases, we anticipate that the symptoms would arise again.

The CDS's principal goals were to rehabilitate a greatly at risk infant, to assist a mother in making reparation for a traumatic separation, and to restore the trusting relationship that had existed before the separation. These goals in turn were met by concomitant modes of intervention. The CDS helped the mother understand Max's communications in the context of his special needs; she enabled her to talk about the range of feelings experienced in this process: hope, doubt, blame, remorse; and she offered Debbie ways of responding to Max until she could take over on her own.

Summary

The interventive work of the Child Development Specialist involves the interweaving of education, understanding and interpretation. The evaluating of the baby's needs, the unravelling of the parents' cares and conflicts, the articulating of feelings, the responding to requests for help and advice, and the strengthening of ties between infant and caregiver, depend most of all on looking, listening, and connecting. Although we found that middle and upper middle class parents are more sophisticated then poor and less educated parents, the major differences in the process as it unfolded had more to do with the sense of control over the process itself—that and the availability of human and material support, including the time to attend, without pressure, to one's deepest concerns.

We think it is clear that we strive to work primarily in the context of a positive transference. We deal frequently with negative feelings toward us, however, and confront them as they arise, making connections between these feelings, the mother's history and the way they affect a child. Although we never model for teaching purposes, we try for a relationship with the mother that can be incorporated as a model for the mother and child.

Setting goals close at hand that are founded on the immediate developmental risks and tasks permits us to move slowly, taking into consideration the different timetables of parents and child. Parents can sometimes make critical changes in caring for their babies before profound internal changes occur which consolidate gains (Miriam and Renee). At other times resources can be found to assist in the transition (Debbie and Max). Often we must settle for less than our hoped-for goals, but can assure developmental fluidity, or to put it more accurately, avoid rigidity and fixation (Jane and Caroline).

In conclusion: our aim always is to free the child from the constraints that would prevent development. It is our belief that we can alter patterns of interaction—relationships—even when the adult's pathology changes little. As a consequence we are dramatically involved in the present, in immediate concerns; and accordingly, we look to the future as much as we consider the past. It is this Janus-like position that makes for the fusion of education and insight, affect and cognition, in our work.

Knock, Knock ... It's No Joke

by
Gene Judge
Readfield, Maine

The last thing I wanted was a "home visitor." My clearest memory of the days following Matt's birth is of wanting to go home from the hospital, get in bed and pull the covers over my head. Looking forward to taking care of the baby, playing with him, giving him a bath, having some coffee, I intended to take the phone off the hook and not see anyone but my husband, my two little boys and a friend or two. No company, no calls, nothing.

Matt was a high risk baby. He was born with spina bifida, developed hydrocephalus within days and underwent repair of his lesion and first shunt installation with one week of his birth. He was delivered by cesarean section.

> *The last thing I wanted was a home visitor for me and my high risk baby. I thought Public Health Nurses were for people who beat their kids and drink too much.*

The floor nurse told me, "After you're home a little while, a Public Health Nurse will be coming to see you." "Really?" I said. "What for?" What I meant was "You must be kidding! Public Health Nurses are for people who beat their kids and drink too much. We do not need a Public Health Nurse coming to our house." Unlike a friend who grew up in Arkansas, where, she said, "everybody had a Public Health Nurse," I grew up in suburban Philadelphia. Only one family I knew had a home visitor. Their father did not work; neither he nor their mother seemed to provide any supervision or physical care for their children. Whenever I saw the mother she was close to drunk. The baby always seemed to have a bottle of Kool-Aid in his mouth. Those kids got away with things we never even thought of doing and lived in circumstances I was sure I could not survive. Families "like that" need home visitors. Families like ours do not. (Perceptions need not be universal, mature or even accurate to be powerful.)

Reason, and needing to do the best I could for EVERYONE, prevailed over my hesitancy. I planned to let the nurse come once, get it over with and be done with it. Afterwards, I could get into bed and THEN pull the covers over my head.

Other parents declare the same objection to visits. While we all want to do the best for our kids, give them whatever surveillance, opinion and care they require, we nonetheless feel very judged when the powers-that-be decide we need to be "visited." Thus put-upon but duty-bound we do our very best to provide the atmosphere we believe "the nurse" is expecting. Some of us give the bathroom one of the only cleanings it will have until the nurse calls again or our mother-in-law comes to visit. Others put "the white glove" plan into action, getting dust from places where no one could see it anyway. Almost all of us scrub our kids till they glow. More resistant families commit to visits they do not keep, either not answering the door when the visitor knocks or simply leaving a few minutes before the designated visit time.

Philip G. Schrag

As it turned out, the Public Health Nurse came for many visits. And while it is definitely true that the nurse used the bathroom on her first visit (I was certain she would—to check it out, of course) as I became familiar with her and her routine I came to appreciate her visits more than I would ever have guessed.

Some visitors are less likely to be resented. Early in Matt's and my life home together we received regular visits from a Child Development Worker. Here was a visitor whose coming conjured up no visions of straight-laced, buxom matrons with blue uniforms, spectacles and sensible shoes. Rather than inspect my suitability for motherhood, the Child Development Worker was going to "work with Matt." What a relief. What a great idea.

As life with Matt developed and visits from both women continued, similarities in them and in their functions became clear. Both women had their own children. They were pleasant, they listened and they chatted. They also had special skills. I liked having the nurse's extra set of knowing eyes when shunt problems caused feeding difficulties and weight problems. Her confirmation of my perceptions of Matt's growth and her affirmation of my handling him were important to me. Matt and I have been without visits for a few years now. He is almost 8 years old, in second grade and growing happily. Holding things together during those first three very stressful years would have been much more difficult for our family without the visits of our Child Development Worker and Public Health Nurse.

Two ideas are important to altering families' perceptions of home visitors. *First, eliminate the stigma: provide every new mother and her family an opportunity to use a home visitor program.* My friend who told me having a home visitor was no big deal came from a place where everybody had a home visitor; all classes, all types, all families. Wiping out the stigma wipes out half the problem with acceptance of a visiting program. Unfortunately policymakers' reactions to universal visiting range from "Well, that's nice, but we can't afford to do that" to "Not everybody needs a home visitor." To the first reaction: can we afford the refusals and series of reticent, resistant, no-show situations that visitors face today? To the second reaction: visiting programs are needed by everybody. Not only could home visitors be more fully helpful to families and children at risk, but also more resourcefully used within well-child programs for every family. Programs that want to insure early emotional adaptability to parenting and assure the emotional health of their children will see the resource that home visitors can provide. Practical information and immediate attention to concerns of parents are most efficiently provided close to the source— in the home. Can we afford not to provide visiting to every family with a new baby?

Two ideas could alter families' perceptions of home visitors. First, provide every new mother with an opportunity to use a home visitor program. Second, guide home visitors in remembering their own past pain.

Second, training required of home visitors should guide prospective workers to look at segments of their own private, intimate lives. Medical knowledge, child development skills, and public health experience are of little significance when the problem at hand is gaining acceptance by a family and admission into sensitive aspects of their lives. Not the technical expertise nor years in training of our two visitors made them valuable resources for our family. Rather, the visitors' ability to look into their own lives for times of utter dismay, distress, crisis and sadness made them much more useful resources for Matt and me.

Visitors, like the rest of the world, need to put bad times behind, and forget in order to get by. But because their contacts with families are so intimate, so fraught with possibility of intrusion on privacy, visitors cannot put their memories of bygone pain and confusion in the closet. Visitors need to take past pain out and look at it every time they knock on families' doors. Visitors need to review their own times of confusion when ignorant and of humility when helpless. They need to remember the harbor that a home can be. In the use of those probably raw memories can the most sensitive, sustained visiting be accomplished.

Home Visiting as a Support to Mothers and Newborns in Europe

In his newly published report, *Maternal Health and Infant Survival*, C. Arden Miller, M.D., Professor and Chairman, Department of Maternal and Child Health, The University of North Carolina, notes that home visiting is an important part of the comprehensive medical and social services provided to pregnant women, newborns and their families in Belgium, Denmark, France, Federal Republic of Germany, Ireland, Netherlands, Norway, Spain, Switzerland and the United Kingdom. These are all countries that spend a lower proportion of their gross national product on health care than the United States and that have better records in birth weights and infant survival. Miller writes:

> **Home visiting is a feature of nearly every one of the ten countries' maternity care, most consistently practiced after delivery than as a part of prenatal care. Home visitors are sometimes midwives but they are more often nurses with special training for home visiting. No country makes use of health aides or indigenous workers as home visitors, except possibly the Netherlands, where an extensive postnatal homemaking service supplements routine postnatal visiting by the midwife or general practitioner who rendered prenatal care.**
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> **Postnatal home visiting in the Netherlands is a central theme of maternity care. Every woman is visited at home either by the midwife or general practitioner. In addition a specially trained maternity home helper stays at home with the mother and infant for up to eight hours a day until the 10th post-partum day! The visitor helps with infant care, shopping, housekeeping, meal preparation and care of older siblings. In 1986 each newborn and mother received an average of 64 hours of postnatal home visiting for a token fee of 40 guilders—about 15 percent of the cost of one day's home help.**
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> **In all countries studied postnatal home visiting is seen as a means for counseling about infant care, for follow-up on the mother's health, for advice on family planning, to initiate or follow-up neonatal screening procedures, and to arrange for additional appointments for the infant and mother.**

Copies of *Maternal Health and Infant Survival: An analysis of medical and social services to pregnant women, newborns and their families in ten European countries, with implications for policy and practice in the United States*, are available for $6 each from NCCIP, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005.

Point of View

Focusing On Prevention In The First Sixty Months

by
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Chairman, Committee On
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The first sixty months are the most critical years in a person's life, a time when the foundations of personality, physique and character are developed. Yet, they are also the forgotten months, when many people unprepared for pregnancy and/or lacking parenting skills, find themselves raising a child. The result, children who are not provided the important health, education and social opportunities needed to maximize their future potential.

Problems not identified and addressed during this stage of life often cannot be completely and permanently corrected during adolescence and adult life. For that reason we need to change the focus of our present human and social service system which only addresses the symptoms of problems.

By focusing on prevention and early identification of potential problems, by involving parents and others who have close contact with young children, we have the opportunity to treat the causes, to make good on the promise of opportunity for the next generation, and to remove barriers to self-sufficiency and productivity.

As Chairman of the National Governors' Association's Human Resources Committee, I initiated an early childhood project entitled—"Focus on the First Sixty Months"— in the fall of 1985. The project grew out of my belief that we are not doing enough to solve the problems associated with early childhood because we are still treating symptoms when we could as easily be attacking their causes. In February, 1986, the committee held a national conference, featuring presentations by individuals from public and private institutions at the state and local levels. These speakers described successful programs aimed at preventing health, education and social problems among children zero to five years of age. (See *Zero to Three*,September, 1986 for the remarks of Irving B. Harris.) At the close of the conference, I called on the NGA to develop a handbook of prevention activities for young children to present to each Governor. In July, 1987 this report, *Focus on the First Sixty Months*, was published.

At the same time, the nation's Governors concluded a year-long effort of five task forces to develop comprehensive state action plans to enhance human potential and bring down the barriers to self-sufficiency. Two fundamental conclusions emerge in the report of the five task forces, *Making America Work: Bringing Down the Barriers.*

- First, human barriers often share common root causes including unmet needs for food, clothing, shelter and medical care, and inadequate basic academic skills, leading to diminished self-esteem and life options.
- Second, the earlier intervention begins the more likely it is to meet with success.

A prevention strategy for young children

For children, the challenge is to prevent the cycle of dependency from claiming another generation. Key elements of a sound prevention strategy for children include ensuring adequate health care, nutrition, family nurturing, and educational, social, and physical development.

Prenatal health care

Prenatal care, including medical care, nutrition, and healthy life habits, is truly an ounce of prevention worth a pound of cure. Early and continuing maternity care is essential. It should include regular medical exams and treatment, nutrition counseling and the food to provide a healthy diet, and safe and appropriate delivery and support services.

Children's health care

Children need decent health care at every stage of development, and health care is critically important as a transition service when individuals move from welfare dependency to self-sufficiency. Good health care begins with comprehensive care early in the mother's pregnancy, throughout labor and delivery, and continues throughout childhood, with a focus on the child's prevention, acute, and chronic health needs.

Preventive and primary health care for children can detect and treat problems that develop during infancy. Providing primary and preventive health care is expensive, but it costs less—both in economic and human terms—to prevent illness and hunger than it does to treat the results.

At a minimum, primary and preventive health care should include:

- Well-baby clinics that provide early, periodic screening, diagnosis, and treatment;
- Full immunization against all preventable childhood disease;
- Supplemental nutrition assistance;
- Medicaid coverage to women and young children with family incomes less than the federal poverty level but over a state's AFDC eligibility levels; and
- Comprehensive adolescent health care services.

Family resource programs

The American family structure has changed over the last fifty years, and many young parents feel a sense of isolation and frustration as they try to work *and* successfully raise children. Parents need to know that they are not alone and that the larger community will support their efforts.

Diverse, independently funded programs have quietly emerged in the last ten years in all kinds of communities to address these needs. Family resource programs can offer parents education, information, advice, and emotional support. Common characteristics of these programs include: child development classes; information and referral services; nutrition counseling; hotlines; peer support groups; parent-child communication skills; and positive discipline techniques.

Child care

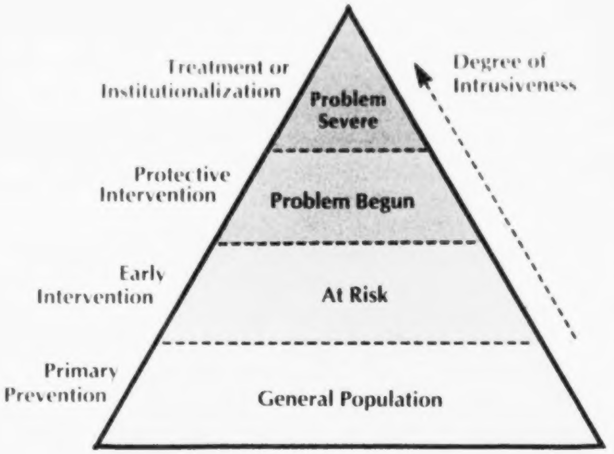
Child care is a critical ancillary service as individuals move from welfare dependency to independency. It is also a critical element in a prevention strategy for children. Quality child care not only provides a safe environment for children while their parents participate in training or work; it also offers valuable education and social opportunities.

What constitutes quality child care? Research suggests the following elements of a "quality" child care program: small group size, high staff-to-child ratios, good health and nutrition standards, parental involvement, and training requirements for caregivers.

Further, as child care strategies are developed, states need to address child care needs in a cohesive, coordinated effort that uses unified standards of availability, quality, and affordability.

A continuum of intervention

As a nation, we have tended to permit the tragedy of treatment needs—the crisis—to overshadow the potential of prevention. Governors, human service agencies, professionals, parents and citizens must begin to refocus their thinking and redirect some of their resources toward prevention programs for some of our youngest citizens. Refocused thinking depends upon a working definition of prevention. This, in turn, helps a state to sort out how many of its current resources can be devoted to true prevention relative to those directed at treatment. A continuum of prevention/intervention can be viewed as a triangle.



Movement from the base of the triangle, the general population, to its apex, severe problems, involves smaller and smaller groups in the population but ever increasing degrees of intrusion into a person's life. As problems become more severe, intervention strategies become more intrusive, more costly, and less effective. Why does a focus on intensive treatment still persist in health and human services programs? First, there are no advocacy groups clamoring for state government to appropriate funds for the general population. Yet, through our past immunization programs, for example, fatal and crippling diseases such as diphtheria, pertussis, congenital rubella, smallpox, and polio were nearly eradicated. Nevertheless, for each of the past four years, the number of children immunized by public programs has dropped by at least 20 percent. Second, there is a longer delay in demonstrable benefit from primary prevention and early intervention than there is from protective intervention and treatment. Removing a young child from an abusive home today and placing him with a foster family is a short-term intervention which can show immediate results. Sending family therapists to that same home for twenty hours per week for several months to prevent removal and placement is a lengthier effort. Waiting another six months for follow-up to demonstrate to legislators and others that early intervention has worked—that removal remains unnecessary—requires patience. Third, service providers who have been trained to provide treatment and have spent their careers doing so, are not easily persuaded to become ardent supporters of prevention.

Patterns of successful prevention

As the handbook *Focus on the First Sixty Months* was prepared, diverse programs were identified from states and localities in every part of the country that have taken a preventive approach and that show promise of success. The nineteen programs selected for inclusion in the handbook address child care, parent-infant relationships, the development of infants and toddlers with disabilities, teenage parents and their children, adoption of special needs children and health care for mothers and infants.

A number of elements seem to be part of the pattern of success of these prevention efforts. Effective programs, we discovered:

- reach out to multiple agencies, whether public or private, in order to deliver an array of needed services;
- often go into families' homes, rather than expecting participants to report to agency offices;
- target multiple problems, albeit a single problem is the initial focus;
- mix funds from public and private, state and local sources;
- include some evaluation effort, to measure the extent of the program's impact and learn whether or not the delivery model needs refinement;
- maximize parent involvement so parents ultimately can be the service providers and advocates for their children; and
- focus on the lower two rungs of the prevention triangle—the general and at-risk populations—where the greatest benefit is likely to be achieved for the least cost and with the least intrusion.

Conclusion

Helping children and families to overcome barriers to healthy development and productive self-sufficiency is a complex process. Multiple points of intervention may be required during a person's lifetime, with approaches from a variety of programs and institutions.

Our Governors' focus on the first sixty months has convinced us that prevention *must* begin early, and that, to be effective, preventive approaches demand commitment and collaboration from all who care about our nation's children and their families.

Our children are the world's greatest resource and our greatest hope for the future. Their ability to build a better future will depend on the foundation we lay for them.

Focus on the First Sixty Months: A Handbook of Promising Prevention Programs for Children Zero to Five Years of Age **is a joint product of the National Governors' Association Committee of Human Resources and Center for Policy Research. The 43-page illustrated publication is available for $12.50 per copy.** ***Making America Work: Bringing Down the Barriers,*** **contains an overview and reports from Governors' task forces on welfare prevention, school dropouts, teen pregnancy, adult literacy and alcohol and drug abuse. The cost of the 133-page report is $15, with bulk rates available. Purchase orders or checks may be made payable to the National Governors' Association and sent to NGA, Hall of the States, 444 North Capitol Street, Washington, D.C. 20001-1572.**

National Center Notes

by Eleanor S. Szanton

As the logo we have been using this year illustrates, 1987 marks the tenth birthday of the National Center for Clinical Infant Programs. We will be celebrating the occasion with a gala dinner in Washington, D.C. on Thursday, December 3, the evening before the opening of our Fifth Biennial National Training Institute.

We hope that readers of *Zero to Three* will join in the birthday festivities and, especially, in honoring **Irving B. Harris** and **Bernard Levy**, who will receive the National Center's first **Selma Fraiberg/Leon Yarrow Distinguished Service Awards**. The birthday dinner program will be rich in substance and emotion. Journalists **Judy Woodruff** and **Al Hunt** will speak about the challenges faced by families caring for infants and toddlers, and original poetry by author and NCCIP Board member **Judith Viorst** will be presented. Please come! You may reserve a place by filling out the appropriate box on the National Training Institute registration form in the June, 1987 *Zero to Three* or on the registration form included in the Training Institute program/brochure that is being mailed to you.

As we have made plans to recognize ten years of NCCIP achievements and to prepare for future challenges, we have heard remarks from a number of friends and colleagues suggesting that the National Center is financially very well taken care of—that our present resources, and access to resources, make us unlikely candidates for charitable contributions. It is not surprising that we should be so regarded. In the ten years of our existence we have been fortunate, through a combination of government support and the commitment of a few very generous individuals and small foundations, to be able to bring our budget to thirty times the size of our tiny 1977 budget. This has happened with a highly dedicated and respected working Board, providing direction to an amazingly small staff.

If NCCIP is to continue its mission, however, we need a broader, more solid financial base. We need your financial support to make these things happen again and again, and for others. We need the help of authors and readers of *Zero to Three* and *Clinical Infant Reports;* of presenters and participants in our national and regional training institutes and intensive courses; of the people who write and call for information, advice and ideas; of those who have used our public policy papers as ammunition in support of new and improved policies for infants in their own locales; of providers and administrators who have been helped to improve the quality and continuity of services within their community and state; and of those who have found useful ideas in our government-supported publications such as *Warning Signals* or *Equals in This Partnership.*

If you read our publications and attend our meetings with support from an agency or organization that cannot itself contribute to NCCIP, please consider making a donation as an individual. The form on the inside back cover of this issue of *Zero to Three* may be used to accompany your contribution, as well as to order a copy of our 1986-87 *Report*.

For Your Information

On July 1, 1987 the Congressionally-appointed National Commission to Prevent Infant Mortality began a one-year mission to develop and publish recommendations for a cohesive and effective national policy to reduce and prevent infant mortality in the United States. The Commission will develop its recommendations by: 1) identifying and examining federal, state, local and private policies and programs that affect infant mortality; 2) identifying current barriers to health care; 3) reviewing recommendations of other bodies; and 4) holding hearings in all areas of the United States with high infant mortality.

The 15-member Commission includes Senator Lawton Chiles (chairman), Representative J. Roy Rowland (vice chairman), Senator Dave Durenburger, Representative Thomas Tauke, former Governor Richard Riley, Governor James Thompson, DHHS Secretary Otis R. Bowen, M.D., Charles Bowsher, Herman A. Hein, M.D., William H. Hollinshead, III, M.D., Julius Richmond, M.D., Barbara D. Matula, Lynda Johnson Robb, California State Senator Diane E. Watson, and Margaret S. Wilson. For further information, write or call Rae Grad, Executive Director, National Commission to Prevent Infant Mortality, Switzer Building, Room 2006, 330 C Street, S.W., Washington, D.C. 20201, tel: (202) 472-1364.

With a grant from the Carnegie Corporation of New York, Erikson Institute is developing a national program designed to train and certify Community Child Safety Specialists who will then conduct programs in their own communities to prevent risk of injury to children from environmental hazards, dangerous child behavior, inappropriate parenting, assaults by familiar persons, and attacks by strangers.

Erikson is looking for potential trainees from ten communities across the United States that are willing to be pilot sites for the programs. Applicants must be willing to spend a week in Chicago for training and must be part of an established child-oriented agency or institution that supports the applicant's involvement in the project. For further information contact Barbara A. Chamberlain, Erikson Institute, 25 West Chicago Avenue, Chicago, Illinois, 60610, tel: (312) 280-7302.

The University of Washington has received a 3-year grant from the U.S. Department of Education which will enable graduate students from special education, social work, educational psychology, speech/language pathology and audiology to take courses outside their own disciplines and work together in a new seminar. Students will be preparing to serve hearing-impaired children from birth to five years and their families through an interdisciplinary, family systems approach. Write or call Judith Stone, Ph.D., Project Coordinator at Experimental Education Unit WJ-10, University of Washington, Seattle, WA 98195, tel: (206) 543-4011 for further information.

The Women's Legal Defense Fund and the Women's Media Project of the NOW Legal Defense Fund, in collaboration with other organizations concerned with parental leave, has developed a press kit on family and medical leave. Included are an overview of the issues, a summary of proposed federal legislation, excerpts from testimony, summaries of surveys, selected newspaper clippings and other materials. For information on obtaining copies of the kit, contact Lynn Thorp at the Women's Media Project, NOW Legal Defense Fund, 1333 H Street, N.W., 11th Floor, Washington, D.C. 20006, tel: (202) 682-0940.

Call for Papers

The Sixth Biennial International Conference on Infant Studies seeks submissions for posters, oral presentations and symposia for its April 21-24, 1988 conference in Washington, D.C. Topic areas include biological processes; cognition and intelligence; early environments; parent-child interaction; perception and attention; communication, play and language; social and emotional develoment; high risk and pediatric issues; and clinical issues. **Abstracts must be postmarked no later than October 15, 1987.** For submission guidelines, write to Dr. Nathan A. Fox, Program Chair, ICIS, University of Maryland, Institute for Child Study, College Park, MD 20742.

The **College of Charleston** and **University of Florida** invite presentations of empirical research and theoretical issues on infancy and other topics for the tenth biennial multidisciplinary Conference on Human Development to be held in Charleston, South Carolina March 17-19, 1988. **Submissions must be postmarked no later than October 31, 1987.** For more information, write to Scott or Patricia Miller, Department of Psychology, University of Florida, Gainesville, FL 32611.

NAACOG, the organization for obstetric, gynecologic and neonatal nurses, seek reports of practice-based research for its conference, "Practice Implications for Perinatal and Women's Health Nursing Research" to be held in Toronto, Canada, July 29-30, 1988. **Abstracts must be postmarked no later than November 28, 1987.** For guidelines contact Charlotte Green, NAACOG, 600 Maryland Avenue, S.W., Suite 200E, Washington, D.C. 20024-2589, tel. 1-800-533-8822.

The Literature Prize Committee of the Margaret S. Mahler Psychiatric Research Foundation will award a $500 prize to the author of an original paper related to Mahler's concepts of separation-individuation in child development. **Papers must be received by December 31, 1987 to be considered for this year.** Write to Dr. Marjorie Harley, Literature Prize Committee, 201 St. Martin's Road, Baltimore, MD 21218.

Publications

Children: Development and Social Issues—Edward F. Zigler and Matia Finn-Stevenson (Lexington, MA: D.C. Heath & Co., 1987) $25.50.

In this undergraduate text, Edward Zigler and Matia Finn-Stevenson attempt to combine presentations of developmental research on physical, cognitive, social and emotional development with discussions of social issues and policy. They emphasize that the study of children must include an appreciation of family settings and relationships. The volume covers development from the prenatal period through adolescence; within each unit, material is organized topically, but the general course of the text is chronological.

A chapter entitled "New Directions in Child Development: A Social Issues Approach" discusses the concept of childhood itself; demographic and family life changes of recent years; and how the needs of children may be addressed through family support programs, advocacy, and the integration of child development research and social policy. In a later chapter, "Social and Emotional Development during Infancy," discussions of parent-child interaction and attachment research are accompanied by material dealing with foster care, infant care leave and services for at-risk and disabled infants. Each unit in the text includes a discussion of atypical development.

The Invulnerable Child—E. James Anthony and Bertram J. Cohler, editors (New York: The Guilford Press, 1987) $35.00.

E. James Anthony and Bertram J. Cohler have brought together in this volume twelve original papers devoted to the issues of resilience and competence. In addition to the editors, contributors include William Beardslee, Robert Cole, Felton Earls, Byron Egeland, Ellen Farber, J. Kirk Felsman, Lawrence Fisher, William Garrison, Judith Goldman, Cynthia Janes, Ronald Kokes, Alice Moriarty, Lois Barclay Murphy, Judith Musick, Edwin Peck, Patricia Perkins, Arnold Sameroff, Ronald Seifer, Katherine Klehr Spencer, Frances Stott, George Vaillant, David Weeks, Julien Worland and Lyman Wynne.

It is only in the last 15 years, Anthony and Cohler note, that clinicians, researchers and theoreticians have begun to shift their attention from disease entities toward "good psychosocial capacities such as competence, coping, creativity and confidence." While the editors do not feel that this field is ready for systematization, they see Murphy and Moriarty's focus on a "continuum of vulnerability" and related concepts as offering a framework for promising preventive interventions. Most of the contributions to this volume, including the Menninger Clinic Longitudinal Coping Study, have a longitudinal perspective. These suggest, notes Cohler, that resilience "appears to be less an enduring characteristic than a process determined by the impact of particular life experiences among persons with particular conceptions of their own life history."

The Malleability of Children—James J. Gallagher and Craig T. Ramey, editors (Baltimore, MD: Paul H. Brookes Publishing Company, 1987) $23.95.

How plastic is the developing organism? The approaches to this question reported in this volume emerged from a conference on the topic hosted by the Frank Porter Graham Child Development Center and sponsored by the Foundation for Child Development. Participants/contributors include Jeffrey Arnett, J. Brooks-Gunn, Bettye Caldwell, Frances Campbell, Glendon Casto, Victor Denenberg, Johanna Freedman, Frank Furstenberg, Nancy Jordan, Irving Lazar, Richard Lerner, Melvin Levine, Robert McCall, John Ogbu, Robert Plomin, Sandra Sears, Evelyn Thoman, Peter Vietze and Edward Zigler, as well as editors James Gallagher and Craig Ramey. Contributions are from the fields of behavioral genetics, experimental psychology, education, anthropology and pediatrics.

While the majority of the chapters in the volume deal with the malleability of young or middle school-age children, Brooks-Gunn and Furstenberg discuss the experiences of adolescent mothers who escape the cycle of poverty. The volume's final section explores the potential impact on public policy regarding services and research of current knowledge about the malleability of children.

Children's Mental Health: Problems and Services—Congress of the United States, Office of Technology Assessment (Washington, D.C., U.S. Government Printing Office, December, 1986). Available from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402, for $8.00.

Requested by Senators Mark Hatfield and Daniel Inouye, this 184-page background paper, prepared by the Office of Technology Assessment, examines the nature of children's mental health problems, the mental health services available to children and the Federal role in providing services. The report states that at least 7.5 million children in the United States (about 12 percent of the nation's 63 million children under 18) are believed to suffer from a mental health problem severe enough to require mental health treatment. In addition to the "diagnosable disorders" described in the American Psychiatric Association's Diagnostic and Statistical Manual, better known as "DSM-III" (in most cases third-party payors will reimburse for treatment only when such disorders are diagnosed), the report discusses environmental factors, including poverty, parental psychopathology, maltreatment, premature birth, a teenage parent, parental divorce, and serious childhood illness, that pose risks to children's mental health.

The report highlights, once again, the gaps between children in need of services and the services available, noting a particular shortage of community based services, case management and coordination across child service systems. Better evaluations of treatment and service systems are called for. The report also notes the effectiveness of prevention programs, stating, "Interventions to provide family support...appear to have substantial potential to prevent and remedy a range of mental health problems and lead to better school achievement in children...Not only have many prevention programs led to positive changes in social, emotional and academic measures, but such programs appear capable of preventing later governmental expenditures through the justice and welfare systems."

National Directory of Children and Youth Services, 1988-89 (Available from National Directory of Children and Youth Services, P.O. Box 1837, Longmont, CO 80502-1837) $53.00.

This 700-page directory is in four parts. Part I contains information on every state's social services, health and welfare, and juvenile justice systems, including descriptions of how services are administered and appropriate contact persons at the state and city/county level. Part II, a new feature of this directory, lists, by state and community, more than 1500 groups or organizations that provide specialized services directly to individuals. Part III, "Who's Who in Federal Children and Youth Services," lists government program administrators; the members, staffs, and jurisdiction of Senate and House committees and subcommittees; national resource centers and clearinghouses; and national organizations serving children and youth, as well as their state and local affiliates. Entries throughout the directory include names, addresses and telephone numbers for agency directors and, in many cases, managers of specialized programs.

Children with Special Health Care Needs: Campaign 87—Surgeon General's Report (Available free of charge from the National Maternal and Child Health Clearinghouse, 38th & R Streets, N.W., Washington, D.C. 20057).

This document, presented by Surgeon General C. Everett Koop at a June, 1987 conference in Houston, Texas, calls for a family-centered, community-based approach to health care for children with special health care needs. Elements of such an approach are described as: recognition that the family is the constant in the child's life; facilitation of parent/professional collaboration; supportive sharing of information with parents; comprehensive policies and programs of emotional and financial support to families; respect for family strengths and diversity; encouragement of normal patterns of living in home and community; incorporation of developmental needs of children and families into health care delivery; parent-to-parent support; and flexibility, accessibility and responsiveness to families in the design of health care delivery systems.

The report outlines seven action steps toward these goals and includes brief descriptions of exemplary projects.

Family-Centered Care for Children with Special Health Care Needs—Terri L. Shelton, Elizabeth S. Jeppson and Beverly H. Johnson (Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016, 1987) $6.00 plus $2.50 shipping and handling.

This 74-page publication, developed with support from the Division of Maternal and Child Health, presents eight components that have been identified by professionals and parents as key elements of a family-centered approach to care for children with chronic illnesses and disabling conditions. (The elements are those enumerated in the Surgeon General's Report, described above).

Each element is defined, followed by specific examples of current programs and policies illustrating a family-centered approach to care. Checklists for parent-professional collaboration, states, communities, hospitals, professional training programs, and research investigations are included for use in evaluating existing and proposed services and policies. A resource section contains information on organizations offering technical assistance, audiovisual and written materials, and program contacts.

A companion pamphlet, "Family-Centered Care: What Does It Mean?," is available free of charge from the Association for the Care of Children's Health.

Children with HIV Infection and Their Families—Report of the Surgeon General's Workshop, April, 1987 (Available free of charge from the National Maternal and Child Health Clearinghouse, 38th & R Streets, N.W., Washington, D.C. 20057).

The Surgeon General's Workshop summarized in this report was designed to review current knowledge about AIDS in children and to make recommendations about future directions in research, prevention and amelioration of the effects of pediatric AIDS. Excerpts are included from presentations on, among other topics, the immunology of pediatric AIDS; the natural history of HIV infection in children; supportive care and treatment of pediatric AIDS; legal issues surrounding medical care and treatment of children, and related research; and implications for service delivery. During the workshop ten work groups reflecting a range of backgrounds, expertise and diversity of opinion developed responses and recommendations, summarized here, on treatment and educational issues for children with HIV infection; risk reduction for maternal/fetal transmission; family and psychosocial issues; models for community and hospital care; and financial issues, among others.

The Six Stages of Parenthood—Ellen Galinsky (Reading, MA: Addison-Wesley Publishing Company, 1987) $10.75, paperback.

Ellen Galinsky, Project Director of Work and Family Life Studies at the Bank Street College of Education, originally published this book in 1981; she describes the years since then as "a period of extremes—difficult problems (for parents) and increasingly creative resources to help solve these problems." She suggests that parents' feelings and actions continue to be misinterpreted if parents and professionals do not understand predictable stages of parental growth. Galinsky identifies and analyzes six such periods: the image-making stage (before birth); the nurturing stage; the authority stage; the interpretive stage; the interdependent stage; and the departure stage. Her observations draw on interviews conducted nationally with 228 parents of 389 children from various economic and geographic backgrounds.

Conference Call

September, 1987

September 30-October 2: The *State Family Based Services Associates of Illinois, Iowa and Minnesota* will hold a national conference on family-based services, "Empowering Families," in Minneapolis, Minnesota. Faculty including Harry Aponte, Edgar Auerswald, Linda Bergland, Robert Horowitz and Douglas Nelson will address family-based service practice, policy and administration and model programs. Contact the Center for Conferences and Institutes, 210 Iowa Memorial Union, The University of Iowa, Iowa City, Iowa 52242, tel: (319) 335-3231.

October, 1987

October 9-10: The *Healthy Mothers, Healthy Babies Coalition* will hold its fourth national meeting in Washington, D.C. Plenary sessions and workshops will focus on ;improving access to perinatal care, adolescent pregnancy, and AIDS issues in perinatal care, as well as on skills building for state and regional coalitions. Write or call Bob Goldberg, March of Dimes, 1275 Mamaroneck Avenue, White Plains, NY 10605, tel. (914) 428-7100.

October 9-11: *UCLA Center for Preventive Psychiatry* in collaboration with the *Department of Pediatrics* will co-sponsor the first annual UCLA National Conference on Preventive Psychiatry, in Santa Monica, California. The theme will be "The Prevention of Mental Health Disturbances in Childhood." Speakers will include Michael B. Rothenberg, Nancy Brill, Leila Beckwith, Dennis D. Drotar, Christoph M. Heinicke, Dennis Cantwell, Richard D. Krugman and Judith Howard. For information contact the Department of Continuing Education in Health Sciences, UCLA Extension, P.O. Box 24901, Los Angeles, CA 90024, tel: (213) 825-6701.

October 16: The *Illinois Association for Infant Mental Health* will hold its fifth annual conference in Chicago, with the theme "The First Year of Life and Beyond: Influences and Issues." Jay Belsky will be the keynote speaker with Jill Reich, Emily Schrag, Bernice Weissbourd, Judith Musick, Fran Stott, Deborah Holmes, Joe Burns, Rick Brinker and Linda Gilkerson as additional presenters. Workshops will focus on medically at risk, environmentally at risk and normal infants. Contact Debbie Holmes, IAIMH, Psychology Department, Loyola University of Chicago, 820 North Michigan Avenue, Chicago, IL 60611, tel: (670)-2030.

October 16-17: *Reach Out to the Parents of an Unknown Child, Inc.* will sponsor a national conference on perinatal bereavement, entitled "Broken Lives, Broken Dreams: The Family's Struggle for Recovery" in Uniondale (Long Island), New York. Topics to be addressed include burial rites, genetic counseling, subsequent pregnancy, multiple pregnancy loss, impact on family members and initiating a parent support group, among others. Contact Pam Riley, Registration Coordinator, 555 North Country Road, St. James, NY 11780, tel. (516) 331-1154.

October 18-20: *Pediatric Nursing* will sponsor its annual conference, entitled "Complex Technologies and Case Managed Care: Problems of National Concern," in Washington, D.C. Speakers will include JoAnne Kaufman, Jeff Lyon, Elizabeth Hogue, Fred Abbey, Mary Donar and Robin Thomas, among others. Write or call Pediatric Nursing Conference, North Woodbury Road, Box 56, Pitman, NJ 08071, tel. (609) 589-2319.

October 18-21: *Parent Care, Inc.* will hold its fourth annual conference, entitled "Parent Care...Moving Through Life," in Philadelphia, PA. Main themes of the conference will be ethical issues and critical care, maximizing the potential of high risk infants, and pregnancy in 1987. Speakers will include Thomas Nunay, Alan Fleischman, Peter Gorski, Judy Bernbaum, Craig Ramey, Karen Shannon, Marie McCormick, Woodie Kessel, Vince Hutchins and Summer Yaffe. Write Parent Care Conference, c/o George Peckham, M.D., Room 2083, Children's Hospital of Philadelphia, 34th Street and Civic Center Blvd., Philadelphia, PA 19104.

October 21-25: The American Academy of Child and Adolescent Psychiatry will hold its 34th annual meeting in Washington, D.C. Speakers will include Julius Richmond and Congressman George Miller. For further information write or call AACAP, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016, tel: (202) 966-7300.

October 22: The *Coalition of Infant/Toddler Educators* and the *Kean College Department of Early Childhood and Family Life Education* will present a conference, "Imagination and Creativity for Infants and Toddlers: On Beyond Sesame Street and Disney" at Kean College, Union, New Jersey. Contact A. Restaino-Kelly, 246 Flanders-Netcong Road, Flanders, NJ 07836, tel. (201) 927-9301.

(continued on page 31)

NCCIP Publications

Publications of the National Center for Clinical Infant Programs include Zero to Three, public policy and special interest publications, the Clinical Infant Report series, and publications of the Division of Maternal and Child Health-supported Project Zero to Three. Since publications are handled by three distribution centers, please be sure to use the correct coupon when ordering.

The following publications are available from: The National Center for Clinical Infant Programs, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005 - (202) 347-0308

Zero to Three

5 issues/year, $18.00/year
$35.00/2 years
$45.00/3 years

Written for professionals working with infants, toddlers and their families, *Zero to Three* includes reports on research in progress, profiles of clinical programs, discussion of current issues in the field, and news of government and private activity, conferences, and publications.

Back issues (from Sept., 1980) and *Index* $4.00/copy

Public Policy Reports

Who Will Mind the Babies?, 1984 No charge
Provides a framework for thinking about the many policy issues involved in developing means of assuring adequate child care opportunities for infants and toddlers under three.

Infants Can't Wait, 1986 $5.00/set, plus $1.50 postage and handling
Reviews the developmental tasks and needs of infants and toddlers, describes support available in this country for their healthy development, and documents needs which are not being met. Proposes two major initiatives to ensure basic and specialized services for young children and their families, as well as strategies for implementation at the federal, state and local levels.

and

Infants Can't Wait: The Numbers, 1986
Companion volume to *Infants Can't Wait*. Documents statistically the birth of infants, the circumstances of their families, risks to their health and lives in the first years of life, their family and community environments, and the sources of their health care.

Other Publications of Special Interest

Maternal Health and Infant Survival: An Analysis of Medical and Social Services to Pregnant Women, Newborns and Their Families in Ten European Countries, with Implications for Policy and Practice in the United States, C. Arden Miller, M.D., 1987 $6.00/copy. Bulk rate available.
Analyzes health care and social supports for pregnant women and their families in ten western European countries with infant mortality rates lower than those in the United States. Analysis, which has major implications for U.S. health policy, reveals a set of strategies which, if implemented, could lead to reduced rates of infant mortality and low birth weight in the United States, and would ultimately reduce public health care expenditures.

Evaluating Service Programs for Infants, Toddlers and Their Families: A Guide for Policy Makers and Funders, 1987 $1.50/copy. Bulk rate available.
Reviews and illustrates the kinds of evaluation efforts funders and policy makers may expect from service providers. It also suggests steps that funders can take to encourage meaningful evaluation initiatives and to foster the use of findings to enhance the physical and emotional health of young children and their families.

Charting Change in Infants, Families and Services: A Guide to Program Evaluation for Administrators and Practitioners, 1987 $4/copy. Bulk rate available.
Suggests that all programs serving young children and families can and should engage in evaluation, and discusses steps that service providers can take to devise evaluation strategies which reflect actual program work and which will provide information needed for program improvement.

Finding the Best Care for Your Infant or Toddler, Laura L. Dittmann, 1985 No charge for single copies
Provides parents with information on elements of good care for infants and toddlers, and answers common questions about choosing care. A brochure published jointly by the National Center for Clinical Infant Programs and the National Association for the Education of Young Children.

Make check payable and mail to National Center for Clinical Infant Programs, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005

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Order Clinical Infant Reports from:

International Universities Press, Inc.

Psychopathology and Adaptation in Infancy and Early Childhood: Principles of Clinical Diagnosis and Preventive Intervention, Report No. 1, Stanley I. Greenspan, M.D., 1981 **$27.50**
Presents a new approach, Greenspan's developmental structuralist approach to the classification of adaptive and pathological personality organizations and behaviors in infancy and early childhood, and discusses the implications of such an approach.

Infants and Parents: Clinical Case Reports, Report No. 2, Sally Provence, M.D., ed., 1983 **$32.50**
Presents detailed case studies illustrating diagnostic and therapeutic issues and methods relating to infant mental health. T. Berry Brazelton, Kyle Pruett, Jeree Pawl and Judith Pekarsky, Alicia Lieberman and Peter Neubauer are among the authors of seven case reports that describe in rich detail how clinicians from a variety of settings use a range of therapeutic approaches to help children and parents in the first years of life.

Infants in Multirisk Families: Case Studies in Preventive Intervention, Report No. 3, Stanley I. Greenspan, M.D., ed., 1987 **$40.00**
Presents four detailed case studies of infants in multirisk families, which provide clinical data for the relatively new field of comprehensive clinical preventive approaches for infants and their families. Conceptual chapters look for patterns and principles in the clinical experience, present criteria for comprehensive developmental diagnosis for infants and very young children, and outline operational criteria for the progression of the therapeutic process itself.

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Project Zero to Three Publications

Under a grant from the Division of Maternal and Child Health, U.S. Department of Health and Human Services, Project Zero to Three aims to have a national impact on improving services to children from birth to three years of age who are disabled or at risk of handicap. Project Zero to Three began in 1983 and is funded through mid 1988. The following publications, developed under the project, are available free of charge.

There Ought to Be a Law? Ensuring State-Wide Services for Disabled and At-Risk Infants and Toddlers, 1985
Outlines the policy options available for establishing or expanding state services for disabled and at-risk infants, factors to consider when undertaking such efforts, and pitfalls to avoid both during the planning process and in the context of the legislation itself.

Keeping Track: Tracking Systems for High-Risk Infants and Young Children, 1985
Discusses realistic goals, instruments, and techniques; criteria for inclusion and discharge; agency or group responsibility, the role of parents; and the limitations imposed by funding restrictions. Includes materials from the tracking systems of Iowa, Maryland, North Carolina, Texas, Utah and Washington.

Equals in This Partnership: Parents of Disabled and At-Risk Infants and Toddlers Speak to Professionals, 1985
Parents share ideas and insights into the joys and difficulties of raising children with special needs, including their experiences with the medical profession and other service providers.

Program Evaluation: Issues, Strategies and Models, 1986
Presents and discusses themes raised in a July, 1984, meeting of administrators, researchers, and clinicians on issues, strategies, and models of evaluating services for disabled and at-risk young children and their families.

Warning Signals: Basic Criteria for Tracking At-Risk Infants and Toddlers, James Blackman, M.D., 1986
Outlines a basic set of criteria useful in selecting infants and toddlers for inclusion in tracking systems designed to follow children at risk for impaired development.

Early Intervention: Concerns of a Career in Nursing: Proceedings of a Symposium in Honor of Camille L. Cook., R.N., M.S.W., 1986
Speakers addressed the distinct role which the nursing profession plays in primary prevention of disorders in infants and young children, in intervention, and in case finding through screening and assessment. They noted problem areas, as well as successes, in the planning and implementation of early intervention programs.

Report Accompanying the Education of the Handicapped Act Amendments (Report #99-860) and Commenting on P.L. 99-457, Linda Gilkerson, Asa Grant Hilliard, III, Emily Schrag, and Jack P. Shonkoff, 1987
Duplicates the Congressional Report, which is no longer available from Congress. The Report contains a summary of the Act, the need for and intent of the law, cost estimates, and the language of the law itself. Comments attempt to place P.L. 99-457 in the broader context of current national initiatives on behalf of very young children and their families.

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November, 1987

November 1-3: *The Division for Early Childhood (DEC) of the Council for Exceptional Children* will hold its third annual national conference on Young Children with Special Needs and Their Families in Denver, Colorado. Contact Early Childhood Conference, c/o Early Childhood Research Institute, 3811 O'Hara Street, Pittsburgh, Pennsylvania 15213, tel: (412) 431-3371.

November 7-10: The **National Perinatal Association's** clinical conference, "The Past and the Future...Perinatal Issues," will be held in St. Louis, Missouri. Issues to be addressed will include ethics, AIDS, consumer expectations, technological developments, catastrophic care, genetics, risk management, teen pregnancy, and public policy, among others. Call or write NPA, 101 1/2 S. Union Street, Alexandria, VA 22314-3323, tel. (703) 549-5523.

November 12-15: The *National Association for the Education of Young Children* will hold its annual conference in Chicago, Illinois. Preconference sessions will include "Federal and state child care strategies: a call for action" presented by the Alliance for Better Child Care; "Prevention programs for at-risk children," presented by the Ounce of Prevention Fund; and "Knowlege and skills to work with infants and toddlers: insights from research and practice and implications for public policy," with Bernice Weissbourd, Alice Honig, Sally Provence and Eleanor Szanton. Tracks on family support, infants/toddlers, child development, and child advocacy/pubic policy will be featured. For information write to NAEYC Registration, 1834 Connecticut Avenue, N.W., Washington, D.C. 20009-5786.

November 13-14: *The Boston Institute for the Development of Infants and Parents, Inc.* will hold a conference on "Clinical Applications of Research in Infant/Parent Relationships" in Boston, Massachusetts. Phyllis Chesler will speak on custody and visitation battles. Other institute and seminar topics will include surrogate motherhood, risk factors in infant-mother attachment, implications of P.L. 99-457, and postnatal prevention of sequelae of prematurity. Cal A.M. Kerzner, BIDIP, tel. (617) 484-6603.

September, 1989

September 20-24: The *World Association for Infant psychiatry and Allied Disciplines* will hold the Fourth World Congress on Infant Psychiatry and Allied Disciplines in Lugano, Switzerland. (Note: this is a change from previously announced dates and site.) For information, contact WAIPAD Secretary-General, Dr. Joy D. Osofsky, Department of Pediatrics, Louisiana State University Medical Center, 1542 Tulane Avenue, New Orleans, LA 70112.

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Bulletin of
NATIONAL CENTER FOR CLINICAL INFANT PROGRAMS VOL. VIII NO. 2 DECEMBER 1987 ISSN 0736-8083

A Chain of Enablement: Using Community-based Programs to Strengthen Relationships Between Teen Parents and Their Infants

by
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Our experiences at the Ounce of Prevention Fund, a network of community-based primary prevention programs in the state of Illinois, have led us to question seriously two widely held tenets of community-based family support programs for children at environmental risk. The first is the notion that improved adult (or adolescent) functioning can, by itself, measurably improve child development outcomes. That is, if a program helps a parent to feel better about herself, and to do well in school or work, she will somehow become a better parent. The second assumption is that parenting is a skill which can be learned, or *re*learned when it is dysfunctional or inadequate.

During our years at the Ounce of Prevention Fund, we have seen in the first case, that improved adult or adolescent functioning in parents is necessary, but far from sufficient, to significantly alter the life chances of disadvantaged children. Second, we have come to see being a parent not as the exercise of a set of skills but, rather, participation in a *relationship*; one which is complex, highly charged emotionally, and strongly

David Kreider

Portions of this paper are based on a chapter entitled "Paraprofessionals, Parenting and Child Development: Understanding the Problems and Seeking Solutions" by Judith S. Musick and Frances M. Stott, to appear in the forthcoming Handbook of Early Intervention, *S. Meisels and J. Shonkoff (Eds.), Cambridge University Press. The preparation of this paper was supported in part by a grant to Judith S. Musick from the Rockefeller Foundation.*

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rooted in individual and family psychology. Intervention approaches designed to strengthen such a relationship may include some educational guidance, but they must be principally aimed at bringing about shifts on deeper, more personal levels. This essay will examine the barriers that prevent community-based programs from focusing on parent-infant relationships and describe a training approach that has increased staff effectiveness in this area.

The developmental vulnerability of infants

In order to grow and develop to their fullest potential, infants need protection from physical and psychological harm, adequate nourishment, help in regulating their own biological rhythms and at least one special responsive adult to whom they can become attached and who will act as a mediator between them and the world. Infants must also have caretakers who treat them as people, creating expectations and prophecies that the children will slowly come to fulfill. As the infant develops, he increasingly needs guidance, structure and experiences which will help him to develop a sense of who he is and what he can do. Infants require opportunities to explore their world, test their autonomy and feel personally effective. As toddlerhood approaches, capacities that will be important for later learning, such as language use, focused attention and interaction with people and objects, are further differentiated and consolidated through experiences perovided in the caregiving environment.

Why might such experiences be absent or minimal in a child's life? What makes us characterize certain infants as being "at risk"?

There are two major pathways which can create or exacerbate vulnerability and dysfunction. One is some form of biological impairment sustained either prenatally or during the perinatal period or one which is a result of a genetic disorder. Such impairments can act directly to cut the young infant off from the growth-facilitating aspects of the environment; indirectly through diminishing parental responsitivity; or, as is so frequently the case, from a complex interaction of the two.

There is, however, another route to developmental vulnerability, another equally serious threat to a child's reaching his fullest capacity, to becoming a competent and useful member of society. That threat is *environmental risk*, a situation in which the child rearing milieu is either deficient in certain key resources and functions or is actively noxious to the developing organism. It is to the issue of preventing developmental failure in children at environmental risk that this paper is addressed. While populations and approaches for biological and environmental risk obviously overlap to some degree, each also calls for special techniques and for the special perspective from which these are derived.

There can be little doubt about the importance and impact of the total ecology of risk, including the influences of extended family, of the community and the larger society and of poverty and social isolation as well. While acknowledging the power of these more macro level variables, program developers also recognize that during infancy parents are the most significant aspects of their child's environment. They are the *mediators* of the effects of poverty, potentially harmful community values, social isolation, psychosocial

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Providing comprehensive support and education services for adolescent mothers will not by itself be sufficient to measurably improve developmental outcomes for their children.

Ounce of Prevention

pathology and difficult or dysfunctional relationships within the family and other social networks. Risk factors impinge upon the parent who then transforms and transmits them to the young child or protects the young child through her caretaking. The child of teen parents in an isolated and impoverished rural area, for example, may suffer from his parents' lack of knowledge and access to material or human resources, as well as from the scarcity of positive role models to guide them in appropriate parenting. A mother who feels defeated by life and helpless to control her own destiny may pass her outlook on to her child through her lowered expections (Clark, 1983) her inability to assert herself in protecting her child from harm (Gershenson, et al., 1987), or through her depression, emotional unavailablity and insensitivity to his needs.

The intervention challenge

The intervention challenge is to reach high-risk parents and children as early as possible, supporting parents and enriching the caregiving environment. One promising strategy for accomplishing this goal is the community-based, family support and education program. Programs of this type generally target *populations* of families at risk rather than individually referred "clients" and seek to promote positive growth in the parents as well as their children.

Teen parents and their children constitute one large and highly vulnerable population of families at risk. As such, they are quite frequently the targets for community-based family support oriented interventions. While research on the relationship between early parenting and child development is relatively sparse, the limited evidence does indicate that the children of teenage mothers are more vulnerable to a variety of health and developmental risks, as well as infant death (*Risking the Future,* Vol. I, 1987). Few of these problems have been found to result *directly* from the age of the mother. Rather, they appear to be at least partially mediated by the social, economic and cultural conditions that are the sequelae of teen pregnancy and parenting. Of particular significance are mother's education, family stability and family size (*Risking the Future,* Vol. I, 1987). In addition, while a mother's age does not seem to affect her child's development directly, there can be little doubt that the conflict between the developmental tasks of adolescence and those of parenting can lead to lowered parental capacities for appropriate, empathic child rearing practices in tune with the needs of the child. These factors converge to create an ecology of risk for the infants of early child bearers and the potentially growth-thwarting environment at which early intervention efforts are aimed.

While, in theory, most programs for teen parents perceive their goals to be the enhancement of both parental and child development, in practice the primary day-to-day focus of most teen parent programs is on helping the young woman. Intervention strategies generally stress early and improved prenatal care, provide psycho-social support, help to build interpersonal and vocational skills and encourage young mothers to continue their education. Those smaller number of services targeted to the infants usually concentrate on helping teen parents learn to provide for the safety, health, and basic care of their children. Although many teenagers have made considerable personal progress as the result of their participation in these programs, their children, like other infants born at environmental risk, often do not fare as well. Helping young parents to return to school, to understand and interact more maturely with their families or to find jobs are clearly important intervention functions. All help to provide teens with skills, self-esteem and relief from undue stress, thus enabling them to better cope with their children. However, adolescent mothers need more than this if we expect to reduce environmental risk for their children. Providing comprehensive home- or center-based support and education services for these young women will not *by itself* be sufficient to measurably improve developmental outcomes for their children.

It is not hard to understand why a parent-child focus is difficult for community programs. Unlike smaller or more intensive intervention/treatment programs, family support programs generally provide a wide range of services for greater numbers of families within their communities, and they are, in most cases, staffed at the direct service level by either trained paraprofessionals from the community or by social work/counseling professionals. Although these service providers may have had experience with adults and adolescents, they usually have had little education, training or work experience related to children and parenting. Many paraprofessionals also lack interest in working with small children because of its traditional image as lower-status work.

The clinical picture derived from our observations of hundreds of infants and toddlers of teen parents indicates a paradoxical mix of adequate cognitive and motor competence paired either with apathy and social disinterest or with disorganized "aggressive" and hyperactive behavior. The infants of teen parents we have seen rarely smile or laugh, and few initiate appropriate social interaction. They seldom cry, even when their parents are hostile or intrusive. People seem to hold little special value for these young children.

Observations of problematic interactions between teenage mothers and their infants give us some clues as to the possible etiology of these troubling developmental patterns. Some mothers and fathers are very active in a "playful" somewhat aggressive way, teasing and over-stimulating their children. Others become angry at their children's developmentally appropriate demands or attempts to explore and assert themselves. They speak very critically and negatively to their young infants and handle them roughly. Still other teen parents recognize what their children are trying to communicate but fail to respond clearly enough to let their children know that they have understood. A lack of "connectedness" characterizes the interactions between these mothers and children, a relational deficit which appears to stem largely from a lack of appropriate, sensitive responsiveness on the part of the mother. This deficit can have serious, adverse consequences for the infant's development of competence.

Strategies affect the child rearing environment

Although many forces are at work to block the development of optimal, growth-facilitating interaction between teenage mothers and their infants, we believe that a good many of these obstacles can be overcome. Unless the problems are severe, focused enabling interventions can help mother-infant relationships to get and stay on track. For this to take place there will need to be well-designed and implemented interventions aimed at positively affecting parenting practices in tandem with early screening and the identification of children in need of intervention/special education services.

For the past several years the program staff of the Ounce of Prevention Fund have been actively engaged in designing and testing strategies to meet this challenge. In the process we have learned a great deal about parents, children, and service providers. We have also come to understand better the formidable barriers to bringing about positive change in a process as complex as parenting. We are convinced that parenting is not simply a skill which can be learned in much the same manner as one learns to sew, cook or drive a car. Rather, it involves participation in a relationship, a way of interacting with, caring for and guiding a young, initially dependent human being. A person's capacity for adequate or "good enough" parenting is deeply intertwined with his or her own personal and psychological health and history in the family of origin. Further, for teen parents, the developmental needs of adolescence bring additional burdens that complicate the already difficult task of parenting. If service providers know little about the complexities of the parenting process, the chances for their interventions with teen parents to have a meaningful impact of the children are relatively small. Indeed, a recent review of the family support and parent education literature (Powell, 1987) backs up our clinical observation that while these programs may successfully reach and support parents as people, few have been able consistently and effectively to reach them as parents.

How can we promote optimal development in children at risk, if we cannot meaningfully affect the child rearing environment? How can we foster positive change if service providers, the potential agents of such changes, are ill equipped for their job? One way, perhaps the only realistic way, is to change that service provider, transforming the way she views and understands parents, children and the parent-child relationship. Five years of concern with this issue have taught us, however, that traditional staff education and training programs are woefully inadequate for the task. Rather, we need to reexamine our approaches to working with parents and begin to develop new strategies more closely tied to both the nature of the problem and the barriers to its solution. The Ounce of Prevention Fund's Developmental Program is one such strategy.

Developmental Program

In 1986 the Ounce of Prevention Fund made the decision to begin providing both traditional developmental screening and on-going observation of the parent-child (and, in many cases, grandparent-child) relationship for all of the children born to adolescent parents in the programs we administer. The creation of the Developmentsl Program, as it has come to be called, grew out of a recognition of the need for direct service staff to have useful techniques for understanding and assessing children's development. Underlying the actual methods devised for the Developmental Program was our commitment to identifying more subtle problems in the realm of socioemotional development. Equally as important was the pressing need for the staff in these programs to become more confident and skillful in enabling teens to function effectively in their parenting roles. On many occasions we had observed lay helpers fail to intervene in or even to notice a variety of potentially serious problems in the children themselves or in parent-child relationships.

It is worth noting that the three years prior to 1986 had been marked by repeated but largely unsuccessful attempts to improve staff performance in this area. Although, for example, we had restructured MELD's Young Mom's (MYM) curriculum (Belbas, 1985) so that it was much more directly focused on child development and parenting issues, we found very little generalization or carry-over into practice. This was true for participants and for staff alike. After exploring a number of possible reasons for their seeming unwillingness to apply this information, we concluded that the teen parents' apparent lack of interest was due, in part, to staff reluctance (or inability) to embrace these ideas. We next instituted a series of parenting and child development workshops which incorporated modeling and hands-on experience with parent-child activities into the expanded training curriculum. However, while program staff were enthusiastic about these parent-child workshops, they were unable to sustain their newly acquired skills once the Ounce of Prevention Fund child development specialists had stepped back into more supervisory roles. In like manner, the teen mothers who had been eager participants in the workshops when they were led by Ounce trainers suddenly lost interest when these activities were taken over by program staff. After lengthy discussions with all levels of field-based program staff, we better understood the barriers to intervention efforts in this content area. We came to see, for example, how service providers' expectations about themselves, and about the children and families they served, were playing a significant role in "blocking" them from truly grasping, let alone using, the material presented. This observation, in combination with our dissatisfaction with our efforts to date, led us to the decision to create a developmental screening program which would include extensive and qualitatively different methods of training for our largely paraprofessional staff.

The Ounce of Prevention Developmental Program combines the use of the Denver Developmental Screening Test (DDST) (Frankenburg & Dodds, 1970) with an instrument designed specifically to assess early socioemotional adjustment, the Parent-Infant Observation Guide (PIOG) (Bernstein, Percansky, & Hans, 1987). The PIOG was developed to capture the more subtle, early precursors of developmental impairment which lie within the realm of socioemotional development. During infancy this development is best observed within the context of parent-child interaction. Problems in this domain have been found to be predictive of developmental lags (e.g., Erickson, Sroufe, & Egeland, 1985; Greenspan, 1982; Greenspan & Poisson, 1983) and can be noted early in the first year of life (Bernstein, Jeremy, & Marcus, 1986).

The DDST and the PIOG are each, in their own way, key elements in the Developmental Program. They are useful not only as screening instruments but, perhaps more significantly, as training tools for community-based staff. Both techniques have provided an opportunity for staff to see children and parents in a new light—they observe systematically not just areas of vulnerability and possible deficit, but strengths and competencies as well. "I didn't know little babies could do that," say providers, as they watch the unfolding of the infants' behavioral repertoire during videotaped assessments of parent-child interaction. The need to communicate with children is underscored by observing

Pinpointing the progress

Shortly after 17 year old Sharon gave birth to her daughter, Paula, mother and baby began to receive home visits from Anita, a paraprofessional home visitor with the Ounce of Prevention Fund's Developmental Program in Chicago, Illinois. Paula had been born two months prematurely; a heart condition necessitated several hospitalizations during her first few months.

Within a year, Paula's health status had improved significantly; her physician pronounced her "out-of-danger." Nevertheless, Sharon continued to feel anxious about the baby's development. She was so eager for Paula to succeed at tasks that she often intruded into her daughter's attempts at mastery. During home visits Anita was able to observe that Sharon was "pressing too hard."

Service providers in the Developmental Program are trained to observe the emotional and developmental functioning of both parent and child and then to use that information to build on the strengths of their relationship. Anita used the Denver Developmental Screening Test to illustrate to Sharon that her daughter was developing in the normal range. She was able to identify specific areas of Paula's healthy development and to point to particular strengths in the parent-child relationship. This process put Sharon at ease and helped her later to look at problems in the interaction. When asked how her relationship with Anita had helped her as a parent, Sharon reflected, "Anita helped me to see how Paula got nervous and irritated whenever I got upset. I realized I didn't want to make my kid like that."

the exquisite responsiveness of even very young infants to the sound of their mother's voice and the sight of her smiling face. Such experiences appear to bring about subtle shifts in providers' perceptions of babies and parents as important and effective beings. At the same time, their gradually increasing ability to notice and better understand developmental or interactional difficulties raises providers' personal sense of competence and efficacy. The Developmental Program enables service providers to focus more directly on children, and to feel more comfortable entering the parent-child relationship. Additionally, the entire training protocol has been structured to model the kinds of reciprocal, interactive roles we expect staff to fulfill vis-a-vis the teen parents who will then, it is hoped, come to behave in similar ways with their children. Training includes observation of parents and children, modeling and supervised hands-on experiences in both assessment and intervention. Both didactic and interactive components have been included. Each nourishes the other and brings about a synergistic experience for the provider/trainee. Such training experiences have resulted in staff gaining a better understanding of their roles as change agents in parent-child relationships. They also have more realistic notions of their abilities, as well as their limitations, in facilitating change. A different level of intervention begins to occur.

Above all, the trainers stress the centrality of the *relationship* between staff and parent. The training is designed to help service providers make empathic connections with parents as well as children. For example, trainers emphasize that pointing out a parent's strengths or skills, instead of ignoring or criticizing, is a key step in building a strong relationship. And although our ratings of temperament are rudimentary, (see Bernstein et al., 1987) they included them because it was important to help staff become more sensitive to individual differences among children and to stimulate them to think about what these differences may mean to parents. With knowledge gained from the training and parent-infant observations, staff are in a stronger position to judge when and how to intervene. Because of their experiences with the Developmental Program to date, staff are now ready for more information about child development and for a broader range of techniques for observing parent-child relationships.

The Developmental Program seeks to create a *chain of enablement* which fosters positive growth in paraprofessional staff so that they in turn can foster such growth in teen parents. This method of training paraprofessionals to focus on the teen as a *parent* is designed to result ultimately in more enabling and nurturing parenting through a structured, well-planned "trickle down" effect. The new perspective gained through the implementation of the Developmental Program at three pilot sites has been incorporated into the thinking of Ounce of Prevention Fund planners about our more traditional parent education andsupport services, in both our center-based and home visiting programs.

Highly interactive, encouraging both staff and parents to participate actively in their own learning, the Developmental Program helps providers to use effectively the strong emotions that surface around relationship issues such as parenting. The program fosters a sense of comfort even with "touchy" topics such as discipline, enabling community-based staff to influence the lives of young families in more meaningful ways. Thus, for example, home visitors trained in the Developmental Program appear to be better able to set limits when they observe teen parents cruelly teasing or slapping their young children for no apparent reason. Now our home visitors propose and model alternatives that seem grounded in their empathy as well as in their knowledge of both parent and child.

Staff who have been participants in the Developmental Program feel confident about tackling interaction problems more directly, especially with those parents with whom they have established a good, supportive relationship. Will this have a meaningful effect on parents' feelings and behavior? Preliminary assessments indicate that it will, for a sizable number of parents. Will this shift in parenting attitude and behavior then have measurable effects on developmental outcomes for the children? We will have to wait and see. However, the nature of the interaction between parent and child has clearly changed as providers have changed. Broader horizons, a sense of efficacy, and a richer, more useful understanding of the parent-child relationship—such shifts cannot be without some effect. We hope that they will act as catalysts for positive growth in young, stressed families, creating healthier parent-child relationships and improving the chances of high-risk *children*, as well as their parents.

References

Belbas, N. MYM Curriculum; Minneapolis: MELD, 1981.

Bernstein, V., Jeremy, R., & Marcus, J. (1986). Mother-infant interaction in multi-problem families: Finding those at risk. *Journal of the Academy of Child Psychiatry*, 25, 631-640.

Bernstein, V., Percansky, C., & Hans, S. (April, 1987). Screening for social-emotional impairment in infants born to teenage mothers. Paper presented at the biennial Conference of the Society for Research in Child Development, Baltimore, MD.

Clark, R. (1983). *Family life and school achievement: Why poor black children succeed or fail*. Chicago: University of Chicago Press.

Erickson, M., Sroufe, L., & Egeland, B. (1985). The relationship between quality of attachment and behavior problems in preschool in a high-risk sample. In I. Bretherton (Ed.), Growing Points in Attachment Theory (pp. 147-166) *Monographs of the Society for Research in Child Development*, 50 (1-2, Serial No. 209).

Frankenburg, W., & Dodds, J. (1970). Denver Developmental Screening Test. Denver: Ladoca Project & Publishing Foundation.

Gershenson, H., Musick, J., Magee, V., Rubino, K., and Rosenberg, D. The prevalence of sexual abuse among teenage mothers. *Journal of Interpersonal Violence*. Accepted for publication, March, 1987 in press.

Greenspan, S. (1982). Developmental morbidity in infants in multi-risk factor families. *Public Health Reports*, 97, 16-23.

Greenspan, S., & Poisson, S. (1983). Greenspan-Lieberman Observation System for Assessment of Caregiver-Infant Interaction During Semi-structured play (GLOS). Division of Maternal and Child Health, HRSA, DHHS, Rockville, MD.

Hayes, C. (Ed.). (1987). *Risking the future: Adolescent sexuality, pregnancy, and childbearing, Vol. I*. Washington, DC: National Academy of Sciences.

Influencing the Responsiveness of Adolescent Mothers to Their Infants

by

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Teenage pregnancy—children having children. The media have assaulted us with the alarming statistics: Each year, one million teens become pregnant. In the U.S., nearly 20 percent of white females and 41 percent of black females become pregnant by the time they are 20. One-sixth of all births in this country are to adolescent girls; in 1984, 56 percent of these mothers were unmarried. As our awareness of the problem of teenage pregnancy has increased, so have efforts at pregnancy prevention. Unfortunately, the efforts have not yet proved to be completely successful. As a result, nearly a half million children are born each year to adolescent mothers.

Are young mothers high-risk parents?

There is a substantial body of literature which documents the social, economic and physical difficulties of teen mothers and their children. Fewer than half of women who have children before the age of 18 obtain the equivalent of a high school education (Mott & Marsiglio, 1985). Women who bear children as teenagers go on to have a higher divorce rate, earn lower wages and have lower participation in the labor force than their cohorts who delayed childbearing (McCarthy & Radish, 1983). In terms of pregnancy itself, young maternal age has been related to higher risks of maternal death and complications (Carey, McCann-Sanford, & Davidson, 1983). While every young mother may not experience these difficulties, membership in the group certainly places parents at risk for a variety of problems which may affect their long-term quality of life.

The CRIIAP (Contingency Response Intervention for Infants of Adolescent Parents) is based on the premise that providing a responsive environment involves more than just stimulating a child.

Children born to teens also comprise a group at risk. They have significantly more perinatal complications, childhood illnesses and disruptive behaviors in school than do children of older mothers. Lower scores on tests of intellectual ability and achievement also have been reported (Lawrence & Merritt, 1983). While these problems are known to exist, their causes are not clear. Some argue that these outcomes are the result of being reared in the impoverished environment frequently associated with the low socio-economic status of the teen parent. Others maintain that the poorer outcomes of these children are related to the unique ways in which young mothers interact with their children.

CRIIAP

What are some of the behavioral differences between younger and older mothers? Several have been reported. Young mothers tend to: 1) look at their babies less often; 2) talk to their babies less often; 3) have less synchronous interactions; 4) hold their infants less closely; 5) prefer physical interactions with their babies to interactions involving verbal and visual stimulation. In general, younger mothers are less responsive to their children than are older mothers (Field, 1980; Jones, Green, & Krauss, 1980).

This quality of caregiver responsiveness may be one of the crucial factors which affects the outcome of children of young mothers. In fact, studies have suggested that for young children, maternal responsiveness is a better predictor of developmental outcome than is maternal stimulation (Jaskir & Lewis, 1981; Lewis & Coates, 1980; Lewis & Goldberg, 1969). (Responsiveness implies that maternal behaviors such as smiling and talking occur in response to infant actions, while stimulation is simply the frequency with which these maternal behaviors occur.) If responsiveness is an important quality for improving child outcome and is absent in this group of "high-risk" parents, then helping teen parents to become more responsive would seem a useful intervention.

The CRIIAP model

Contingency Response Intervention for Infants of Adolescent Parents (CRIIAP) was funded by the Handicapped Children's Early Education Program as a demonstration project to develop and evaluate an intervention model to improve the responsiveness of adolescent mothers to their infants. We chose to focus on the quality of maternal responsiveness for several reasons. Many early intervention models focus on increasing the input, or amount of stimulation, that a child receives. However, providing a responsive environment involves more than just stimulating a child. It requires that children play a part in determining when these exchanges with the environment will occur. By making stimulation by the caregiver contingent upon the child's behavior, the responsive caregiver provides the opportunity for co-occurrences. These are events which occur together or in close temporal proximity such that they are viewed by the child as related events. When children participate in these events, as by striking a mobile that then moves and makes a sound or by smiling and then receiving the caregiver's attention, they learn that they can have an effect on their environment. Piaget suggested that co-occurrences provide the foundation for later cognitive development. Based on theoretical and empirical support, therefore, we chose to focus on responsiveness as the means to improve what is generically referred to as "parenting" or "caregiving." The choice of responsiveness as the focus of intervention with adolescents was further supported by the literature, which suggested that young mothers are less responsive caregivers than older mothers.

Given the scope of problems experienced by teenage mothers (e.g., school drop-out, repeat pregnancies), it was not defensible to target only the interaction of mother and child for intervention. We found it obligatory to emphasize problem-solving and life planning skills, as well, and attempted to address other needs of the mother and her family.

Since becoming familiar with the families' needs was central to our intervention, we used a home-based approach. However, the young mothers also were invited to a monthly support/education group. Many of the mothers found themselves socially isolated after having a child because of dropping out of school or lack of transportation. In the monthly groups, they had the opportunity to meet young women in similar situations in a positive, supportive atmosphere. The group meetings also served to reinforce intervention by providing an opportunity to discuss and demonstrate topics relating to child development, child health and life planning skills.

Working with teens

The CRIIAP intervention, based on a contingent response model of parent-infant interaction, was developed and evaluated with a small group of teen mothers and their infants. The mothers were all low-income women who were 17 or younger when they became pregnant with their first child. They were recruited through a community midwifery clinic which serves public health department patients and other low-income women.

Participation in the project was voluntary. Participants in the program were seen in home visits by staff members on a weekly basis until the infant was 4 months old. After that, visits were scheduled on a bi-weekly or monthly basis, depending on the needs ofthe parent. A major barrier to operationalizing this plan appeared, as the hazards of working with teens became quickly apparent in low participation rates. Even those mothers who were interested in our program were inconsistent about being present for scheduled home visits. During the initial months of intervention, mothers were present for visits about half the time. (We found that other programs involving teens encountered similar problems if they were not located in a school or some other setting where the teens were a "captive audience.")

We resolved the problem with a combination of contracting and incentives. Each mother recruited for the program signed an agreement stating that she would be at home with her baby, would provide a quiet place to work, and would do the activities brought by home visitor. If these conditions were met, the mother received $5.00 at the end of the visit. The incentives program was controversial among agency staff. Nevertheless, legal counsel approved the concept and project staff found that the quality as well as the quantity of home visits improved as a result of incentives. The young mothers appeared to respond well to having clear, specific expectations stated for them. We had found that many teens had difficulty with the abstract concept of "enhancing their infants' development" and lacked the intrinsic motivation to work consistently with their infants. They seemed to need more immediate and more tangible benefits for themselves in order to become involved in activities with their babies. Our agency is currently investigating use of incentives for other services related to adolescent health care.

Levels of adolescent development

While adolescent parent behaviors may be confusing to the naive observer, they are consistent with the literature on adolscent development. Some teens, generally those in late adolescence, are mature enough to be consistent caregivers, to think about and plan for the future, and to attend to their babies' needs before their own. These teen parents, incidentally, were puzzled when we introduced incentives. They could not understand why a mother would need to be paid to take part in our program.

Other teens are unable to identify themselves as a parent. They remain in the role of a child and relate to their infants as siblings. These early adolescents had no interest in our program. They seemed to have a great deal of difficulty viewing their child as a person with needs separate from their own. Most often they were not the primary caregiver for the child.

Many of our participants, and those who responded best to the incentives we offered, were *middle adolescents*. They had difficulty thinking of their future or their child's future. They were peer-oriented and much more interested in being with friends than in being home with their babies for home visits. Yet once provided with "external motivation," they were able to become more attentive and responsive to their infants' cues.

As the project evolved and we learned more about adolescents, our approach to intervention changed. We began to assess each teen's level of development and to adapt intervention strategies accordingly. While the content of the sessions was consistent, we found ways of helping the less mature teen learn to take her infant's perspective. We did much more modeling and were more direct in giving corrective feedback to this group. In contrast, we approached the mature teen with a more facilitative, indirect style. We often presented her with information and then followed her interests in a home visit, while emphasizing principles of responsiveness. We felt that our intervention became more effective as we became more sensitive to the needs and abilities of each young mother.

The CRIIAP intervention

The initial phase of the program evolved into a group of guided learning activities; *Discovering Your Baby: Activities for the New Parent.* Designed for use with infants from birth to 4 months of age, the purpose of these activities is to help the new parent become an accurate observer of her infant's behavior and to develop appropriate responses to her infant's cues. Activities are written in simple language and emphasize experiential learning by the parent. In a typical activity (see box) the parent engages in play with her child and observes his responses. Then the parent is asked to indicate which responses she observed and to decide how she should respond to her infant based on his behavior. The activities can be self-directed or done with assistance from a service provider who may model activities and give corrective feedback.

The second phase of intervention focused on helping parents use play as a means of providing learning opportunities for their children while continuing to emphasize the principles of responsiveness. Aspects

SAMPLE DISCOVERY ACTIVITIES

Objective 2A To Find Ways Your Baby Uses Her Hearing.

Most babies like to listen. How does *your* baby use her hearing? Do these activities to find out . . .

1) Use a rattle, bell, or some other noise maker (see objective 2B, Activity 2 for ideas on making rattles).

A) Hold the rattle out of your baby's sight, but far from her ear (your arm's length). Shake it, sometimes loud and sometimes gently. What does your baby do? Check as many as you see.

___ Baby looks away or pulls back
___ Doesn't seem to hear; no change in activity
___ Baby looks for the sound
___ Baby makes faces
___ Baby gets still
___ Baby smiles
___ Baby yawns
___ Baby moves more
___ Baby fusses

B) Now move it closer to your baby's ear (6" to 12"). Again, shake it loudly sometimes and gently sometimes. What does your baby do? Check as many as you see.

___ Baby looks away or pulls back
___ Doesn't seem to hear; no change in activity
___ Baby looks for the sound
___ Baby makes faces
___ Baby gets still
___ Baby smiles
___ Baby yawns
___ Baby moves more
___ Baby fusses

C) Now move it right next to your baby's ear. Again, shake it loudly sometimes and gently sometimes. What does your baby do? Check as many as you see.

___ Baby looks away or pulls back
___ Doesn't seem to hear; no change in activity
___ Baby looks for the sound
___ Baby makes faces
___ Baby gets still
___ Baby smiles
___ Baby yawns
___ Baby moves more
___ Baby fusses

Does your baby seem to hear better when things are:
___ far ___ close (6" to 12") ___ very close (right next to ear)

How can you tell? ______________________________

____

____

Do *you* like a loud noise in your ear? Probably not?

Did your baby like it when you made a loud noise right next to her ear? ___ Yes ___ No of these activities were based on Nursing Child Assessment Satellite Training (NCAST) principles developed by Barnard and her associates at the University of Washington. In this phase of the intervention, parents learned to respond to their children's engagement/disengagement cues during play situations. Intervention also focused on teaching parents to use clear language and to give children opportunities to learn new tasks without adult interference. Again the emphasis was on the parent responding to child-initiated behaviors rather than having the parent direct the activity. These activities continued until the child was 8 to 12 months old.

In addition to focusing on parent-infant interaction, project staff attempted to identify other needs of the teen mothers and their families and to facilitate use of community resources that assisted in meeting those needs. Staff dealt with a variety of issues: gaining access to social service programs, securing day care and returning to school and preventing repeat unintended pregnancies. The poorly developed problem-solving skills of many less mature teens made it difficult for them to identify and implement solutions to their problems. Tasks that seemed routine to an adult, such as applying for Medicaid or other forms of assistance, were difficult for these mothers. Staff helped them learn the process of identifying and completing each step involved in a task, from making an initial phone call to returning the necessary paperwork. Some mothers needed a great deal of support in order to learn successfully to locate and use available resources.

CRIIAP TRAINING MATERIALS

- *BRIEF REPORTS*
  Project newsletter addressing theoretical and empirical issues, project research results, etc. Complimentary copies available.
- *DISCOVERING YOUR BABY: ACTIVITIES FOR THE NEW PARENT*
  Guided learning activities for the new parent. Complimentary copies available.
- *PROJECT MANUAL*
  Implementation guide for project components. Describes theoretical basis for model and procedures for intervention and evaluation.
- *TRAINING TAPES*
  Videotapes of home visitor-parent-infant interactions which provide training in a contingency response approach.
- *TECHNICAL ASSISTANCE*
  Staff are available to present one or more components of the project.

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Evaluation

The project was evaluated using the Nursing Child Assessment Scales (NCAS—Feeding and Teaching). Observations of feeding interactions were done every 4 months from birth to 12 months. Observations of teaching interactions were done at 4 month intervals, beginning at infant age of 4 months and ending at 12 months. In addition, evaluations were done with a comparison group of similar mothers (primiparous, low-income, 17 and younger) who did not participate in the intervention program. Mothers in the comparison group were given the opportunity to participate in the monthly groups, but received no home intervention.

Outcome

Statistical analyzes of the NCAS scores indicated that mothers who participateed in the intervention program became more responsive to their infants while the comparison group mothers did not. Because the two groups were small, these findings should be viewed as encouraging, but not conclusive. At best, they indicate that it may be possible to teach adolescent parents to become more responsive caregivers. Further evaluation of the intervention with more participants is necessary before definitive statements about its effectiveness can be made.

In evaluating outcomes on an individual basis, project staff observed that the maturity of the teen mother affected how much she benefited from the program. Early adolescents were more likely to drop out of the project. Mothers who were more mature were more responsive to their children initially or quickly became more responsive. This seemed to be true whether they were in the program or in the comparison group. Less mature mothers who participated seemed to change the most as a result of intervention. Their NCAS scores indicated that they became more responsive, while those in the comparison group did not improve. These results suggest that the middle adolescent mother may benefit the most from programs such as ours. The more mature late adolescent may need support and information, but less directive guidance from service providers. Staff also found that the late adolescent mother often needs to learn about community resources which she then can utilize independently; the less mature mother needs more supervision in meeting her needs by making use of such resources.

Barriers to long-term change

While our results suggest that teen mothers became more responsive to their infants after involvement in the CRIIAP Project, there were limits to what was accomplished. Only four of eleven intervention mothers completed or resumed their education after having the child. Four of the seven who did not return to school had repeat pregnancies. Thus, the life situations of the teen mothers and their children did not necessarily improve, indicating that their long-term social and economic outcome may not be as positive as the short-term gains.

Several factors appeared to have contributed to the lack of change in the lives of these teen mothers. Family support was immensely important. The mothers who succeeded in resuming their education were those whose parents encouraged them to return to school and who provided the resources necessary to achieve that goal. This may have included securing child care for the baby, transporting the mother and baby when necessary, or providing financial support. Many of the young mothers who did not return to school or who became pregnant again came from disorganized homes where parents were unable to provide the supervision and support necessary for the mother to set goals and work toward them. These kinds of problems, related to family structure and values, are not easily addressed.

Other barriers to successful outcome for the teen mothers were a lack of the most crucial community resources. For example, there was a profound scarcity of day care for infants from low-income families. If the family could not provide child care, then the teen mother had few alternatives but to drop out of school. (None of the schools in the area provided in-school day care, which would have made an impact.) Lack of transportation and the absence of telephones in many homes also made it more difficult for some families to utilize those resources that were available to them.

In summary, the CRIIAP Project was successful in accomplishing its goal of generating a model for improving teens' caregiving skills. The success was balanced by additional revelations and insights. Unless intervention is adapted to the level of the consumer, it is not likely to be successful. Early adolescents require very intensive efforts which are likely to yield limited success. Middle adolescents will benefit most from systematic intervention. Finally, late adolescents appear to succeed even without substantial intervention.

Levels of maturity did not necessarily correspond to chronological age. One 14 year old mother functioned like a "late adolescent;" several 17 year old mothers looked like "early adolescents;" as do, unfortunately, many older mothers. If it became necessary to prioritize groups to receive services, middle adolescents and their offspring would be first. Early adolescents are not ready to benefit from the intervention, and their offspring would best be served by alternate skilled caregivers.

Other services are needed to complement a specific intervention like CRIIAP's. The future of the teen and her child will be enhanced if she stays in school and does not get pregnant again during adolescence. Some public health programs, schools and social service agencies have developed successful pregnancy prevention and in-school day care programs. A coordinated community effort that includes pre-parent and parent training together with these other components is necessary to improve the outcome of teens' offspring.

References

Carey, W.B., McCann-Sanford, T., & Davidson, E.C. (1983). Adolescent age and obstetric risk. In E.R. McAnarney, (Ed.), *Premature adolescent pregnancy and parenthood.* (need page numbers) New York: Grune & Stratton.

Field, T. (1980). Interactions of preterm and term infants with their lower- and middle-class teenage-age and adult mothers. In T. Field, S. Goldberg, D. Stern, and A. Sostek, (Eds.), *High risk infants and children.* New York: Academic Press.

Jaskir, J., & Lewis, M. (1981, April). *A factor analytic study of mother-infant interactions at 3, 12, and 24 months.* Paper presented at the annual meeting of the Eastern Psychological Association, New York.

Jones, F.A., Green, V., & Krauss, D.R. (1980). Maternal responsiveness of primiparous mothers during the post partum period: Age differences. *Pediatrics, 65,* 679.

Lawrence, R.A., & Merritt, T.A. (1983). Infants of adolescent mothers: Perinatal, neonatal, and infancy outcome. In E.R. McAnarney (Ed.), *Premature adolescent pregnancy and parenthood* (pp. 149-168). New York: Grune & Stratton.

Lewis, M., & Coates, D.L. (1980). Mother-infant interactions and cognitive development in twelve week old infants. *Infant Behavior and Development, 3,* 95-105.

Lewis, M., & Goldberg, S. (1969). Perceptual-cognitive development in infancy: A generalized expectancy model as a function of the mother-infant interaction. *Merrill-Palmer Quarterly, 15,* 81-100.

McCarthy, J., & Radish, E.S. (1983). Education and childbearing among teenagers. In E.R. McAnarney (Ed.), *Premature adolescent pregnancy and parenthood* (pp. 279-292). New York: Grune & Stratton.

Mott, F.L., & Marsiglio, W. (1985). Early childbearing and completion of high school. *Family Planning Perspectives, 17,* 5-12.

Call for Papers

The **Family Resource Coalition** will hold its second national conference October 6-9, 1988 in Chicago, Illinois. Proposals for workshops and panels on advocacy and public awareness; practice, theory and applied research; family resource program models; evaluation of family resource programs; and program operation and management are sought. **All proposals must reach the Coalition by December 31, 1987.** For guidelines and other information, write or call Carol Levine, Family Resource Coalition, 230 North Michigan Avenue, #1625, Chicago, IL 60601, tel: (312) 726-4750.

The June, 1989 issue of the **Journal of Pediatric Psychology** will focus on family issues in children's health. Manuscripts on topics such as the role of families in health and illness behaviors, coping and adjustment, health promotion, child abuse, and nonintentional injuries are solicited. Empirical studies and evaluation reports are particularly encouraged. **The deadline for manuscripts is September 15, 1988.** For information and guidelines contact Michael C. Roberts, Ph.D., Department of Psychology, Box 2968, The University of Alabama, Tuscaloosa, AL 35487-2968.

Children's Environments Quarterly is a new journal designed to improve understanding of the relationships between children and the physical environment through the publication of a broad range of theory, research and research applications. Submissions are sought for "theme issues" and an annual "Collected Papers" issue. For further information, write or call Roger A. Hart, Editor, *Children's Environments Quarterly,* CUNY Graduate School and University Center, 33 West 42nd Street, New York, NY 10036, tel: (212) 790-4551.

Perspectives on Practice

Editors' note: The Perspectives on Practice department of Zero to Three offers an opportunity for readers to share case material that illustrates a particular intervention approach, that exemplifies a pattern of parent-infant interaction, or that poses a special challenge to the practitioner's emotions, skills and resources. Manuscripts should be submitted for consideration to Emily Schrag, Zero to Three, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005.

CAROL, MELVIN and YOLANDA

by
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When I first saw Carol she was 12, shy and 3 months pregnant. Beside her was the 18 year old father of her child. She came from a large family. Her mother was only 28, looked 40, was unmarried, and had six children younger than Carol. They were on welfare and lived in a public housing apartment. Carol was tall and well developed for 12. Sex came as something natural in her life and she felt that a baby was part of it. Carol didn't like school very much, and thought pregnancy would be a good reason to drop out, but she thought she would go back . . . someday.

It wasn't hard to like Carol. She was so responsive to all attention. She read everything she could and always asked for more. She had many sexual misconceptions and felt women should be subservient to men in relationships with them. Her boyfriend's name was Melvin. He said he wanted a baby. He wanted to see if he really could father a child.

The social worker and I visited Carol at home. It wasn't the worst home I'd ever seen, but it came close. Outside, bottles and paper of all description was littered about; inside, shades were drawn and the house was very dark. The furniture consisted of a couch, a table with a few broken chairs, one bedroom suite, and two cots. There was no pattern to eating or sleeping. "Wherever" or "whenever" seemed to be the rule. Several children were home, out of school, and when asked why they were there, Carol's mother replied they just wouldn't get ready that morning. A 4 year old walked around the house sucking on a dirty, empty bottle.

Carol and Melvin frequently telephoned me at night, asking questions regarding her pregnancy. He genuinely seemed concerned about Carol. He provided transportation for her to clinic and bought her gifts of food and clothing. She wanted to marry Melvin, but he wanted to pay off his car.

Carol miscarried soon after our home visit. I went to see her in the hospital, and she really didn't know what was happening. She seemed to understand she had lost the baby, but the reality of the situation seemed beyond her grasp. She didn't seem depressed about her loss, she just wanted to know if it was her fault and if Melvin would blame her. Melvin did want to blame someone, because he didn't understand that a 20 week fetus could not survive. He became very hostile towards the hospital personnel and felt "they" had killed his baby. I listened with as much empathy as I could muster. Secretly I thanked God for letting her miscarry as she did not and could not understand all the responsibilities of raising a child. I finally ended up showing them a picture of an actual dead fetus at 20 weeks that I found in a medical textbook. They accepted the written data on the immaturity of the lungs at that stage, and were satisfied that the hospital had not killed their baby.

Carol came back to clinic after losing the fetus for her four week check. She would not accept any birth control because she and Melvin still wanted their baby. I talked about her age (now 13), the increased risks, interference with school, with being carefree. Nothing I could say would change her mind. I told her I cared for her and her health, and to call me if she needed me.

I had a hard time coping with my parental feelings. I wanted her to understand the risks involved but I was completely helpless. I didn't hear from her for 3 months. When I did it was to ask if I would see her in clinic—she was pregnant again. I was angry and sad at the same time. I told her I was upset that she was pregnant, but that of course I would see her again.

She had started back to school after her miscarriage and said she planned to continue in school with this pregnancy. She also said she and Melvin would get married as soon as he paid a few more bills.

She was very anxious to "do right" with this pregnancy. Her anxiety was so great that the social worker and I began to see her every two weeks in clinic. She soon dropped out of school, saying the risk was too great for her to continue.

Carol spotted at 22 weeks gestation. She was placed on bedrest and the spotting ceased. We both breathed a sigh of relief. Carol and Melvin told me they had stopped having sex before the spotting episode because they felt it would be better for the baby. There were no other medical problems until 28 weeks when her membranes spontaneously ruptured one night. She called me immediately. I was stunned. I thought we had made it, but now she was losing another one! She rushed to the emergency room and was taken on to labor and delivery. I tried to console her, but I wanted consoling myself. We listened together as the fetal monitor recorded the tiny fetal heart rate. Labor and delivery prepared the nursery for a premature. The tiny baby girl was miraculously born alive! Throughout the short labor Carol had obeyed all instructions but seemed to know the infant could expire at any point. Again the severity of the situation could not be understood by someone so young. The baby was rushed to the Intensive Care Nursery for life support aids.

Instead of asking for the baby, Carol kept asking for Melvin. I could have choked him! I called his place of employment and told them he was needed at the hospital right away. Didn't he know he was needed?

The placenta came out in fragments. It seemed forever until Carol and her baby were in stable condition. I felt exhausted but elated too, because the baby, although only weighing 1 pound 14 ounces, had a chance to live. She was named Yolanda.

In the next few days the baby increased in strength and her condition improved. Melvin came every day at different times to visit the baby and Carol. Because he worked, he had to come at odd hours but he came faithfully. I observed him one night with Yolanda in the nursery. He was gentle and loving with her. He even "baby talked" her, not the every day picture of a macho black man!

On Carol's fourth postpartum day, her temperature spiked and she began hemorrhaging. She was taken back to delivery and a D&C was done. Her fever continued. She was placed on a cooling mattress and analgesics and antibiotics were pumped in intravenously. Her fever did not go down. Melvin raced back and forth between his two sick girls while still maintaining his job. Carol became ever increasingly demanding with him but he seemed to understand that she was sick and he did as she wished.

The decision was made to do a hysterectomy because she was so badly infected. A hysterectomy! At 13? I hated and blamed myself. Why had I not talked harder to prevent Carol from getting pregnant? I was very depressed. The social worker and I talked long hours at night giving each other support so we could support Carol. We visited her often in the hospital. She seemed unaffected. How could she not look and act depressed? She still smiled and mechanically stated she understood she could no longer bear children. She repeated the words the doctors had instructed her in, but they were only words without meaning to her. She seemed to enjoy all the attention she was getting, especially from her mother. This was probably the first time in Carol's life that she could remember having her mother all to herself. When Carol was about to be wheeled down to the operating room on the stretcher, she whispered a question to me—could she still have sex? I quickly told her that she could.

After her hysterectomy, all was removed except one tube and one ovary, she became afebrile and was released soon after that. She didn't call me as much as she had when she was pregnant. I felt feelings of loss but consoled myself with the fact that she could reach me if and when she needed me.

Yolanda was discharged several months later at 4 pounds and 6 ounces without apparent problems.

I saw Carol, Melvin, and Yolanda in the pediatric follow-up clinic soon after that. They had a picture album showing Yolanda's growth since birth. They were obviously happy and proud parents. They were not married yet, but in every respect seemed to be. I felt so happy for them and fantasized that they would live happily ever after.

I heard from the nursery social worker that Yolanda was in the hospital with hydrocephaly. She was shunted but already had some brain damage. How much more could Carol stand? Her only child with hydrocephaly! Carol didn't call me but I kept up with her progress through the nursery social worker. Apparently she had taken this last trauma in stride.

A few weeks later I saw Carol and Yolanda in clinic. Carol had the baby dressed like a little doll (in real doll clothing) and was smiling proudly at her baby. I looked at Yolanda and absorbed the shock that her head was twice its normal size. Carol seemed to have no less love for her infant. I wondered if I could be that way if I had an infant with hydrocephaly or any other defect? Would I take care of my child as well as this 13 year old was doing?

Carol turned 14, she's still not in school, she is still single, she is on welfare, and she is sterile. I wonder when she will realize all of this? In 10 years when she is all of 24 years of age will she finally cry all the tears that she has not shed? When the realization hits, I hope there is a professional close by who will meet Carol more than halfway and give her the love and support that she deserves.

For your information

The Mental Health Law Project, a national public interest organization, recently worked with parents and service providers to organize an early intervention advocacy coalition in Maryland. The experience convinced MHLP staff and supporters that organized grassroots support will be essential for the successful implementation of P.L. 99-457, the Education for the Handicapped Act Amendments of 1986. The Project has prepared a brochure including questions and answers about P.L. 99-457 and action steps needed to launch a state early intervention advocacy effort. For copies of the brochure and/or for information and technical assistance in organizing a grassroots coalition to shape your state's early intervention program under P.L. 99-457, contact Beth Carter or Margaret Lorber, Mental Health Law Project EI Advocacy Program, 2021 L Street, #800, Washington, DC 20036, tel: (202) 467-5730.

The **Child Welfare League of America (CWLA)** has begun "The Children's Presidential Campaign '88" to make children a priority in the 1988 presidential election. CWLA has developed a twelve-point program for children addressing issues of income security, housing, nutrition, child care, health, abused and neglected children, adopted children, foster care services, adolescents, and children who are physically and mentally challenged. CWLA will provide information briefings and technical assitance to agencies and individuals interested in organizing children's presidential campaigns in their states. For information, contact Donita B. Hicks, Director, Children's Presidential Campaign '88, c/o CWLA, 440 First Street, N.W., Suite 310, Washington, DC 20001-2085, tel: (202) 638-2952.

Point of View

Preventing Young Children From Failing Is America's Best Investment

by
Owen B. Butler
Retired Chairman of The Procter & Gamble Company
and
Vice Chairman of the Committee for Economic Development

The nation's public schools have traditionally offered a common pathway out of poverty and a roadway to the American Dream. But today, in too many communities, the schools are ill equipped to deal with the many problems of the educationally disadvantaged—the 30 percent of children facing major risk of educational failure and lifelong dependency. While the education reform movement has primarily focused on raising standards in the nation's public schools, it has all but ignored the root causes of failure for the nearly one million young people who drop out each year or who graduate semi-literate and virtually unemployable.

Children in Need calls for a national campaign of early and sustained involvement in the lives of disadvantaged children as the only way to help them break the shackles of lifelong dependency and failure.

Students who come from poor families are three times more likely to become dropouts than are students who come from more economically advantaged homes, and schools with higher percentages of poor students have significantly higher dropout rates than do schools with fewer poor students. This is hardly surprising: Children of the poor suffer more frequently from almost every form of childhood deficiency, including infant mortality, gross malnutrition, recurrent and untreated health problems, psychological and physical stress, child abuse, and learning disabilities.

Many disadvantaged teenagers who are dropout-bound compound their situation by bearing children before they have the maturity and skills to handle the demands of parenthood, ensnaring themselves and their offspring in a web of poverty and despair.

In recognition of these problems, the Committee for Economic Development (CED) issued a new report in September, titled *Children in Need: Investment Strategies for the Educationally Disadvantaged,* which calls for a national campaign of early and sustained involvement in the lives of disadvantaged children as the only way to help them break the shackles of lifelong dependency and failure.

In this report CED asks the nation to confront the need to change the way we deal with children born into poverty, discrimination, or neglect. This is the only way we can reverse the likelihood that we will have a permanent and growing educational underclass in this nation. By continuing to allow nearly one-third of our children to fail, we will not only impoverish these children, we will impoverish our nation—culturally, politically and economically.

Children in Need recognizes the urgent need for early prevention to forestall problems that can lead to later educational failure. It is the first report by a major national business organization to argue that the health and social development of poor infants and children are key factors in their readiness for formal schooling.

The report recommends working with both disadvantaged mothers—many of whom are young and underskilled—and their children from pregnancy through birth and to age five, when most children enter the public school system. Among its major recommendations, the report calls for programs to provide disadvantaged expectant mothers with necessary prenatal care, with education in parenting skills and with the encouragement and support they need in order to stay in school and successfully complete their education. Of course, young fathers should not be left out of the equation, and greater emphasis needs to be placed on pregnancy prevention and dropout prevention efforts for both young girls and boys.

For infants and toddlers from disadvantaged homes the report advocates vastly improved infant care, better access to child care for poor working parents and young parents still in school, and quality pre-school programs for all disadvantaged three and four year olds. The report also looks beyond early prevention to recommend the important changes needed in public schools that serve the disadvantaged so that they can become more effective places of learning that meet the needs of the whole child.

Why business cares

CED's recommendations met with some surprise in the media and in the Congress. After all, CED is a private, nonpartisan, nonprofit organization which is funded primarily by business, and its Board of Trustees is made up of more than 225 top corporate executives. The question many people ask me, as chairman of the subcommittee that produced the report, is why a business organization like CED is devoting so much of its time and resources to sounding the alarm on behalf of disadvantaged children?

The answer lies in the groundwork CED laid more than five years ago in two studies that focused on improving the nation's productivity and international competitiveness. The research and discussion that went into framing those reports threw into sharp focus the relationship between education, productivity and our nation's ability to compete in an increasingly challenging global economy. While completing those studies, our trustees realized that the single most important contributor to productivity was not tools but people, and that ultimately the ability of the U.S. to compete successfully would depend upon our success in developing our human resources to their highest possible level. With that thought in mind, we brought

David Kreider

together a subcommittee of top business and education leaders for a three-year study of our nation's schools and the business role in education reform. The subcommittee's work resulted in the 1985 report *Investing in Our Children: Business and the Public Schools*, which spotlighted the profound gap that exists between the skills needed in the workplace and those being learned by students in our schools. It provided a framework for general education reform, highlighted the need for more intensive business-school partnership and helped bring the issue of preschool education for the disadvantaged to the forefront of national debate.

Investment strategies for the educationally disadvantaged

Yet even as we completed that study, we could see that our work was not finished. Our research into the best educational investment strategies convinced us that the old maxim, "an ounce of prevention is worth a pound of cure," was as valid as ever. In investigating educational quality it became apparent that the students who later drop out, become pregnant, or turn to crime are easy to identify long before high school, usually by third grade and often much earlier.

Children in Need represents a call from business leaders for every sector of our nation to make the needs of disadvantaged children a top priority. As heads of major corporations, we are asking the business community to recognize the profound stake it has in ensuring that every child has access to quality education and is able to benefit from that education. In our report we call for the business community to help lead coalitions of business, education, community groups, parent organizations, foundations and every level of government to help address these profound problems.

If we fail to make the investment needed now to break this vicious cycle of poverty and ignorance, we will only have to pay more later, both financially and in terms of human misery. Every class of dropouts costs this nation about $240 billion over the course of their lifetimes in lost wages and unpaid taxes. The cost in crime control, welfare payments, remedial education, and health and social services account for billions more.

Should present trends continue, our industries will be unable to grow and compete internationally because a growing educational underclass will lack the necessary skills and work habits to function productively on the job. Moreover, they will lack the levels of literacy needed to make informed choices about their lives or to take part in the political process.

We know enough to act

The shame of our society is that we do know enough to prevent so many from failing and to reverse some of the damage wrought by childhood poverty. For instance, we know that working with three and four year olds and their parents in Head Start programs yields measurable benefits. A study by the Select Committee on Children, Youth and Families of the U.S. Congress found that for every $1 invested in quality preschool education, we can expect a substantial return of $4.75 in the reduced costs of remedial education, welfare, crime and other social services.

We also know that the earlier we start, the less costly our efforts will be. David Hamburg, president of the Carnegie Corporation, has pointed out that intensive care for low-birth-weight babies can easily cost taxpayers $1,000 a day. Yet prenatal care for a pregnant teenager can cost as little as $600 per client.

With the right kind of support from caring adults—who may be parents, teachers, close relatives or religious and community leaders—many children from disadvantaged backgrounds are able to overcome early deprivation and excel in school. Yet a disproportionate number of disadvantaged children cannot even benefit from quality education because they are damaged physically, intellectually and emotionally long before they enter the classroom.

Children of children

One out of every six babies born in the United States today is the child of a teenage mother. Fewer than 50 percent of teenage mothers graduate from high school, and teen fathers are 40 percent less likely to graduate than their peers who are not parents. Although the teen birth rate has recently declined somewhat, it still is the highest of the industrial nations—about twice as high as that of Great Britain, Canada and France, three times the rate of Sweden and six times that of The Netherlands.

Girls who have babies at age fifteen, sixteen, or even younger frequently become pregnancy dropouts from school and society, forever dependent on government support. Children born to teenage mothers face special health risks; they are often born prematurely or suffer from low birth weight, conditions that predispose them to developmental retardation and a variety of learning disabilities. It is not surprising then that a recent U.S. Department of Justice study found that as many as 40 percent of the teenagers arrested for crimes in the United States are diagnosed as learning disabled. Such disabilities begin in the womb and in the first months and years of life; for the poor, these problems often go undetected and untreated until it is too late.

The issue of teen parenthood needs to be addressed through a combination of policies and programs at the federal, state and local levels. *Children in Need* makes a number of specific recommendations in the area of early intervention that we believe can help children embark and stay on the road to successful lives. These include:

- **Encouraging pregnant teenagers and those with babies to stay in school and develop good job skills, so that they can become independent and self-supporting.**
- **Providing parenting education for both mothers and fathers. Teenage and other at-risk parents need to be taught how to care properly for their children and provide them with appropriate health care, nutrition and intellectual stimulation. Studies of child-care and preschool programs show that the best results come from programs designed to improve parenting skills and home life.**
- **Providing prenatal and postnatal care for pregnant teens and other high-risk mothers and family health care and developmental screening for their children. Many avoidable learning deficiencies are the result of poor health care and nutrition during pregnancy and early childhood.**
- **Offering quality child-care arrangements for teenagers in school and for poor working parents. Child-care should stress social skills, language development, and school readiness. Programs for teen parents that provide onsite day care offer excellent opportunities to teach good parenting skills.**
- **Sponsoring pregnancy prevention programs that educate young girls and boys to their options in life other than early parenting.**
- **Making quality preschool programs available to all disadvantaged three and four year olds. Quality preschool programs have been shown to improve school readiness, enhance later academic and social performance, and reduce the need for remedial education during the school year.**

Other needed reforms

In stressing the necessity of early prevention, the CED report does not mean to downplay the need to press ahead with education reform. In fact, the CED report warns that there is little sense in giving disadvantaged children a head start if the schools that await them fail to build on early successes and instead promote failure. The graduating class of the year 2000 entered kindergarten this year. Unless important changes are made in the quality of their educational experience, we can expect close to one out of every three to drop out before receiving a diploma. They will join nearly ten million others now in school who are likely never to finish their education. Can the nation really afford to keep wasting such potential?

In *Children in Need*, we call for sweeping reform of the education system to make schools more responsive to the needs of the disadvantaged. We call for fundamental restructuring of the way schools are organized, managed, staffed and financed. We support school-based management, greater decision-making ability for teachers with a demonstrated commitment to teaching the disadvantaged, smaller schools and smaller classes, a variety of social support, health care, and extracurricular programs and greater parental involvement.

The report also recommends carefully targeted programs that combine comprehensive educational, employment, health and social services for students still in school and for dropouts. These programs should combine work experience with education in basic skills, operate in an alternative setting that promotes motivation and self-esteem, and provide long-term evaluation and continuity in funding.

Who is responsible?

Development and implementation of many of the investment strategies CED recommends will require both significant increases in funding and better targeting in order to assure that the necessary resources reach those children most in need.

Business has an important stake in helping to improve the way America's youth are prepared for the future. In *Children in Need*, we urge business to become a driving force in the community on behalf of initiatives for disadvantaged youngsters, particularly in communities that need stronger support for early prevention programs and where there is little political clout to get these programs properly funded, initiated and administered. In an unlikely stance for a major business organization, the CED report contains strong support for increased funding for both early prevention and public education programs on the local, state and federal government levels. In fact, CED's trustees were adamant in concluding that any strategy that aims to improve the development and education of disadvantaged children must recognize the need for additional resources or it is doomed to failure.

While the federal government must play an active role in addressing the special needs of the disadvantaged, we do not expect it to shoulder the full burden of the needed programs. Instead, we see the federal role as one of leveraging resources and pointing the way for state and local governments, who, ultimately, have the responsibility for education. The federal government can play an important role in establishing demonstration projects and providing the research that can track programs and evaluate progress.

The CED report does, however, ask the federal government to reaffirm its long-standing commitment to ensuring that the disadvantaged have access to quality education. Without equity, excellence is impossible. We consider it essential that funding of Chapter I remedial reading and mathematics programs and Head Start is brought up to levels sufficient to ensure that all eligible children are served. These programs have proven their ability to narrow the gap in achievement between disadvantaged and nondisadvantaged children.

Where do we go from here?

Some of the changes CED advocates can be put in place now; others address fundamental, structural weaknesses in our public schools and in our policies toward children and youths. This will be a long and difficult process. It is an arduous political task to encourage cooperation among all levels of government and a multiplicity of constituencies.

But the business community now recognizes its stake in our nation's children. And the business community's concern extends far beyond the narrow dollars-and-cents issues. We view this as a survival issue. Whether the nation remains free and prosperous will depend on our ability to give every American child the opportunity to develop to his or her full potential. As business leaders, we believe it is incumbent upon us to become a persuasive voice for the millions of disadvantaged children who cannot speak out for themselves.

Children in Need: Investment Strategies for the Educationally Disadvantaged can be ordered from the Committee for Economic Development, Distribution Division, 477 Madison Avenue, New York, NY 10022. Single copies are $10.50 each, plus 10 percent for postage and handling. Bulk order discounts are available. Orders under $50.00 must be prepaid.

Help Wanted

The **Office of Special Education Programs (OSEP)**, working collaboratively with the **Bureau of Maternal and Child Health and Resources Development** and the **Administration on Developmental Disabilities,** is initiating a call to the field for quality procedures for developing, implementing and monitoring individual family service plans (ISFP) to comply with the requirements of P.L. 99-457.

OSEP is interested in gathering 2-page descriptions (with assessment instruments or IFSP's attached) of the following: 1) procedures for assessing family needs and strengths—copies of instruments or description of procedures, including any information on reliability and validity; 2) procedures for team involvement and family-professional partnerships in developing the IFSP; 3) an actual IFSP developed for a child and family, with all personally identifiable information deleted; 4) procedures for insuring the effective implementation of the IFSP; and 5) procedures for monitoring the implementation of the IFSP.

Quality practices will be disseminated to the field upon the permission of the person submitting the material and with full credit given to the author. **Descriptions and materials should be submitted no later than January 8, 1988 to Dr. Ann Turnbull, Office of Special Education, Switzer Building, Room 3082, 330 C Street, S.W., Washington, D.C. 20202.**

NOTE: The original December 15 deadline for submissions was extended by OSEP for readers of *Zero to Three*.

The Center for Development of Early Education at Kamehameha Schools is conducting a survey to document the current use of home visiting in the United States, the purpose for which it is used and for whom. The information from this survey will be made available to federal agencies concerned with future funding and policy decisions for family support programs in the home. The Center is anxious to include as many programs as possible. **Staff of home visiting programs who have not received a questionnaire by January 1, 1988, or who need additional copies, should contact Dr. Richard Roberts, Center for Development of Early Education at Kamehameha Schools, Pre-Kindergarten Programs, Kapalama Heights, Honolulu, Hawaii 96817, tel: (808) 832-3015.**

National Center Notes

by Eleanor S. Szanton

NCCIP has taken on three new initiatives in the past few months:

Early Childhood/Technical Assistance Center (EC/TAC)

As many of you know, under a grant from the Division of Maternal and Child Health of the U.S. Public Health Service, the National Center has developed Project Zero to Three over the past four years. This project provided technical assistance and enhanced the networking capabilities of state agency administrators in fifteen states which have been particularly active in developing comprehensive early intervention services for infants and toddlers who are disabled or at risk. Now, NCCIP will take part in a 5-year contract from the U.S. Department of Education to provide technical assistance to all 50 states (and territories) endeavoring to organize early intervention services for children from birth through two years of age under Part H of Public Law 99-457, the 1986 amendments to the Education of the Handicapped Act. The **Frank Porter Graham Child Development Center** of the University of North Carolina is the prime contractor and coordinator of the Early Childhood Technical Assistance Center. Other participating organizations in addition to **NCCIP** are the **Federation for Children with Special Needs,** the **Georgetown Child Development Center,** and the **National Association of State Directors of Special Education.**

NCCIP's particular areas of expertise in this contract will be in day care and in prevention and related areas. In addition to NCCIP's senior program staff, several NCCIP Board members will participate in the technical assistance effort: **Linda Gilkerson** serves on the Advisory Committee; **Sally Provence** and **Jack Shonkoff** will serve as expert consultants in several areas of the contract. We are very pleased to continue our work with state administrators to improve services to disabled and at-risk infants, toddlers and their families, and we especially look forward to contact with administrators in the 35 states with whom we have not had earlier opportunities to collaborate.

State agency approaches to infant day care:

NCCIP has long taken a role in articulating what infants and toddlers need in day care (as, for example, NCCIP's contribution to the development of the Child Development Associate credential for working with infants and toddlers as well as the Family Day Care credential; NCCIP's chapter on "Developmentally Appropriate Care for Children from Birth to Age 3" in NAEYC's *Developmentally Appropriate Practice* for its Center Accreditation Project; and NCCIP's advice to the Children's Foundation's *Better Baby Care* materials for family day care providers.) NCCIP has also been working with state administrators on early intervention issues (see above). It now seems a logical next step to develop our capability to be of use to state administrators who are regulating and/or monitoring center-based and family day care for infants and toddlers. With a grant from the A.L. Mailman Family Foundation, NCCIP has begun developing contacts and expertise about the wide range of issues which affect day care policy; has brought together state day care administrators from California, Kentucky, New Jersey, Washington and the District of Columbia to discuss issues of common concern; and is preparing resource materials for state agencies. The National Center will seek to expand this capability in future years.

Training Approaches for Skills and Knowledge (TASK)

The training of practitioners who work with infants, toddlers and their families has been a major concern of the National Center for Clinical Infant Programs since its founding. Because knowledge about the earliest years of life comes from so many scientific disciplines, because the challenges to development faced by young children can be so complex, and because skill and sensitivity in working with infants and their parents can come from so many professional and life experiences, there can be no single route to competence as an "infant specialist." At the same time, NCCIP is convinced that there are core competencies that should be possessed by *any* practitioner who works with infants and families, whatever his or her discipline or work setting.

Such a statement seems particularly important at a time when the increased demand for providers of services to infants and toddlers means that many practitioners without training in infant development, or without an appreciation of the interrelatedness of lines of development, or without experience in collaborating with families and other professionals on behalf of young children are being called upon to work in infancy programs.

With support from a private foundation, NCCIP will soon begin a three-year project to: 1) define what professionals in a range of professions need to know to work effectively with infants, toddlers and their families; and 2) work with consumer groups, professional organizations, training institutions and government agencies to reach consensus around these competencies and use them in their own training materials and activities.

We will keep you informed as each of these projects progresses, and we would be very glad to have ideas or leads you might wish to share with us about any of them.

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We are pleased to report that **Mary D. Salter Ainsworth,** a Life Member of NCCIP, has received the C. Anderson Aldrich Award in Child Development, presented by the Section on Child Development of the American Academy of Pediatrics. Other active or life members of the NCCIP Board who have received the Award are: **T. Berry Brazelton, Morris Green, Arthur Parmelee, Sally Provence, Julius Richmond,** and **Edward Zigler.**

A Continuing Dialogue on Infant Day Care

Attachment Theory and Day Care Research

ROSS A. THOMPSON, *Department of Psychology, University of Nebraska*

At the risk of helping to turn volumes 7 and 8 of *Zero to Three* into the *Journal of Day Care Debate,* I am writing to contribute another viewpoint to the fruitful exchanges emerging from Jay Belsky's review of day care research ((*Zero to Three,* September 1986). It concerns the use of attachment theory as a prism through which Belsky interprets findings from this research literature.

Attachment theory figures prominently in Belsky's review in several ways. First, it galvanizes his concern about the possibly detrimental effects of day care because, as he notes, attachment theory underscores the importance of the infant's confidence in the caregiver's accessibility which might be threatened by early, repeated daily separations. Second, attachment theory inclines Belsky to interpret a baby's distance-maintenance or avoidance of the mother as reflecting an insecure attachment relationship (rather than, say, precocious independence or simply a different social style). Third, attachment theory leads Belsky to associate this infantile behavior with the antisocial behavior sometimes observed in preschoolers with day care experience, arguing that early attachment insecurity places a child "at-risk" for subsequent social difficulties of this kind.

Each of these theoretical assumptions is controversial, but it is the third assumption which merits especially critical attention by students of early development. It is one thing to argue that early, extended day care experience may not foster optimal socioemotional functioning in infancy (a point to which I shall later return); it is another to suggest that such experiences provide a psychological foundation leading to later difficulties in the preschool and school-age years. The latter view is consistent with our longstanding beliefs about infancy as a formative period, but implies much less plasticity to early development than may actually be true (see Thompson, in press[a]). If Belsky is correct, it certainly heightens the concern of parents and practitioners as well as researchers about how early day care experience may shape not only current but also subsequent socioemotional development.

Although Belsky is correct that attachment theorists argue that there is continuity in how successfully a child negotiates developmentally appropriate tasks—with a secure attachment in infancy providing the basis for more optimal later socioemotional functioning (see Ainsworth, Blehar, Waters, & Wall, 1978; Sroufe, 1979)—such a view is not entirely supported by the relevant research evidence. Instead, in a comprehensive review of the attachment literature, my colleagues and I recently concluded that whether the security of attachment predicts later socioemotional functioning depends on the degree of consistency in the child's caregiving conditions over time (see Lamb, Thompson, Gardner, & Charnov, 1985). When attachment *is* predictive of later behavior, it is usually when there is substantial consistency in caregiving influences over this period (indeed, some samples have been specifically selected for consistency in care). In contrast, when conditions of care change markedly (e.g., a new primary caregiver, or the same caregiver under markedly different social conditions, or additions or changes in substitute caregivers), attachment relationships themselves tend to change and do not predict the child's later behavior very well.

We thus concluded that a secure or insecure attachment *by itself* does not necessarily foreshadow later socioemotional functioning, but rather early attachment status *combined with* consistent caregiving influences which help to maintain and support early influences on the child may predict later development. This makes sense, of course, when we appreciate that a young child's personality is shaped by long-term caregiving influences, with contemporary influences having at least as important an effect on the child as past influences. Over time, for example, experiences of sensitive, responsive parental care which contributed initially to a secure attachment may lead also to a child's positive, prosocial behavior as a preschooler, but not unless those patterns of care are maintained. In a sense, then, a secure or insecure attachment in infancy provides a picture of *current* conditions of care, but cannot predict the child's later behavior unless those caregiving influences are maintained over time to shape the child's later development also.

This is an important conclusion when discussing the effects of early day care experience on attachment relationships and later socioemotional behavior, because day care children regularly experience changes in their conditions of care (e.g., transitions to new caregivers or to new care arrangements). Even if early day care experience contributed to the development of insecure attachments (a conclusion of considerable debate, as Belsky acknowledges), the later consequences of this would be hard to predict in light of the diverse subsequent caregiving influences these children are likely to experience. And, in fact, this is consistent with the empirical picture: Preschoolers with day care experience show a range of positive as well as negative social behaviors, they exhibit negative behaviors which often diminish and disappear over time, and there are strong links between later behavior and the quality of care the child experiences (Belsky, in press). This picture is sensible if we assume that children's behavior as preschoolers is affected not only by early day care experience, but also by subsequent experiences of care which may maintain or change these early influences.

In short, a secure or insecure attachment in infancy, by itself, does not lead inevitably to certain psychosocial outcomes in children; it is the ongoing quality and consistency of care which is important. If caregiving conditions change in the early years (which is more likely in day care than home-reared children), it may be more difficult to predict later outcomes based on early caregiving influences alone. We need to look, in addition, at the quality and consistency of later care.

This is not meant to imply that if early day care experience contributes to insecure attachments, we should not be concerned. Rather, we should not assume that the child's later socioemotional functioning is necessarily impaired as a result. But *does* early day care experience contribute to attachment insecurity? My own review of the evidence cited by Belsky leaves me with considerable doubt that it does (see Thompson, in press [b]). One reason is that the evidence suggesting that early day care experience contributes to avoidant attachments is very weak. For example, in Belsky's own study (Belsky & Rovine, in press) and in Barglow's research (Barglow, Vaughn, & Molitor, 1987), between 26 percent and 31 percent of their day care subgroups were rated insecure-avoidant in the Strange Situation, which is somewhat higher than average. However, their home-reared or low-day-care comparison groups also had a higher-than-usual proportion of securely attached infants (65 percent to 79 percent, depending on the subsample), leading to group differences which were partly a result of characteristics of the *comparison* groups used. When I instead compared the patterns of attachment described by Ainsworth and her colleagues (1978), I could find no significant differences in the security of attachment between them. In short, while infants with substantial day care experience in these studies *did* show a somewhat elevated proportion of avoidance attachments (although the majority were securely attached), the difference was not substantial enough to mark their overall pattern of attachments as significantly different from the norm.

Furthermore, we must exercise considerable caution in interpreting avoidant behavior in the Strange Situation as reflecting an insecure attachment relationship when day care samples are concerned. It is wise to remember that the Strange Situation has been validated primarily for American middle-class samples, the large majority of which were likely to have been home-reared at the time these studies were conducted. The cross-cultural studies of attachment using the Strange Situation procedure (see Lamb et al., 1985, for a review) has convinced most researchers that a child's personal history must be considered very carefully when interpreting his or her Strange Situation behavior, because variations in cultural child-rearing practices (such as those relating to the frequency of contact with strangers, regularity of separations from mother, and other factors) seem to affect Strange Situation behavior in ways which may be independent of the security of the infant-mother attachment relationship. Since day care infants differ from home-reared babies in precisely those ways which these cross-cultural studies have found to be important (i.e., experience with strangers, separations from mother), it is reasonable to question whether the Strange Situation behavior of day care infants means the same thing as it does with home-reared infants. Until we are certain that it does, the use of the Strange Situation as the primary index of attachment in evaluating the effects of early day care experience must be done with considerable interpretational caution.

There are other reasons to doubt that the evidence linking early day care experience to attachment insecurity is sufficiently compelling to describe early day care as a "risk factor" for problems in early socioemotional development (see Thompson, in press[b]). Taken together, I think the only scientifically justifiable conclusion which social scientists can offer when asked by policymakers about the effects of early day care experience is: "We still don't know." While such a conclusion is inconsistent with the researcher's desire to be authoritative and knowledgeable when asked for policy recommendations, it not only fairly represents the current state of our knowledge in this area, but also acknowledges the other considerations which must legitimately play a role in this policy debate.

One such issue which has remained surprisingly unaddressed by researchers concerns the quality of care which is normatively available to young families seeking out-of-home care for their infants and young children. It is very expensive to provide good quality infant care, and the quality of day care which is accessible to such families is further undermined by the financial limitations they experience in the cost of care they can afford, as well as the generally high turnover of child-care workers, widespread social perceptions that caring for young children is essentially "unskilled" labor, and the general unwillingness of state and federal governments to regulate the quality of early care or subsidize its expense (see Young & Zigler, 1986). Although we have some information concerning the links between the quality of early care and its effects on young children (see, for example, Ruopp, Travers, Glantz, & Coelen, 1979), we have yet to apply these findings to a systematic analysis of the quality of care which is *typically* available—and affordable—to most of the families who employ such services.

Given the impediments to the availability of high quality yet affordable out-of-home care for young children noted above, I remain concerned about the growing use of infant day care services in this country. But not for the reasons Belsky indicates. Instead, I am concerned that the quality of care which is normatively accessible to young families does not satisfy the minimal standards which existing research indicates fosters healthy early socioemotional development. But this remains a research issue, and one which I hope the critics and advocates of early out-of-home care will address shortly.

References

Ainsworth, M.D.S., Blehar, M.C., Waters, E., & Wall, S. (1978). *Patterns of attachment.* Hillsdale, NJ: Erlbaum.

Barglow, F., Vaughn, B.E., & Molitor, N. (1987). Effects of maternal absence due to employment on the quality of infant-mother attachment in a low-risk sample. *Child Development, 58,* 945-954.

Belsky, J. (in press). The "effects" of infant day care reconsidered. *Early Childhood Research Quarterly,* in press.

Belsky, J., & Rovine, M.J. (in press). Nonmaternal care in the first year of life and the security of infant-parent attachment. *Child Development,* in press.

Lamb, M.E., Thompson, R.A., Gardner, W.P., & Charnov, E.L. (1985). *Infant-mother attachment.* Hillsdale, NJ: Erlbaum.

Ruopp, R., Travers, J., Glantz, F., & Coelen, C. (1979). *Children at the center.* Cambridge, MA: Abt Associates.

Sroufe, L.A. (1979). Socioemotional development. In J.D. Osofsky (Ed.), *Handbook of infant development* (pp. 462-516). New York: Wiley.

Thompson, R.A. (in press[a]). Construction and reconstruction of early attachments: Taking perspective on attachment theory and research. In D.P. Keating & H. Rosen (Eds.), *Constructivist perspectives on atypical development and developmental psychopathology.* Hillsdale, NJ: Erlbaum.

Thompson, R.A. (in press[b]). The effects of infant day care through the prism of attachment theory: A critical appraisal. *Early Childhood Research Quarterly,* in press.

Young, K.T., & Zigler, E. (1986). Infant and toddler day care: Regulations and policy implications. *American Journal of Orthopsychiatry, 56,* 43-55.

From Another Perspective

ROBERT E. GUTTENTAG, Ph.D., *Department of Psychology, University of North Carolina at Greensboro*

In the discussion of day care in recent issues of *Zero to Three*, considerable attention has been paid to the reliability and validity of some of the measures used to assess the effects of different forms of child rearing. Much less attention seems to be given, in this discussion and elsewhere, to exactly what range and types of effects we should even consider. Most of the research has been concerned with the potential long-term impact of the conditions of rearing on the individual's development, and even those measures which are taken of the child's current functioning (e.g., attachment to mother as indexed by behavior in the Ainsworth Strange Situation) have typically been chosen because they are predictive of later levels of adjustment. Noticeably absent from the discussion is any evaluation of the rearing conditions from the infant's or child's own immediate point of view. That is, no consideration has been given to whether children are themselves happier with or prefer a particular form or style of child rearing.

Clearly, parents and other caretakers impose experiences upon children and demand behaviors of children that children find aversive, and equally often experiences are withheld that children would prefer. A simple example is that most caretakers do not allow children to eat whatever foods the children would like. However, these actions on the part of caretakers are taken with the reasonable belief that the actions are important for the children's long-term well being.

In the absence of reasonable expectations concerning long-term impact, however, it seems appropriate to take the child's preferences and feelings into account. We certainly would not inflict physical discomfort upon a child even if it could be shown that no long-term harm would accrue. With regard to child rearing, it would seem, similarly, that we are justified in treating children in a manner *they* find aversive or which they do not prefer only when such treatment is in some sense "for their own good."

I do not wish to suggest that caretakers should always let children get their own way—far from it. Nor should factors such as the family's economic well being and the simple convenience of caretaking from the parent's perspective be ignored. However, there seems to be very little data evaluating patterns of child rearing from the child's point of view. Collecting such data would be a daunting task to be sure, and it is probably unrealistic to presume that any easily generalizable conclusions could be drawn. Nonetheless, to ignore completely the quality of the experience from the infants' and children's perspectives is to deny the validity of their feelings. There should be more to evaluating the quality of child rearing than measuring its impact on later functioning.

A special reprint from *Zero to Three*, entitled "Infant Day Care: A Continuing Dialogue," is now available for $4.00 from the National Center for Clinical Infant Programs, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005.

This 20-page document includes Jay Belsky's article, "Infant Day Care: A Cause for Concern?," which originally appeared in the September, 1986 issue of *Zero to Three*, along with responses by Deborah Phillips and others reprinted from the February, 1987 issue and further responses by Peter Barglow and John Davis reprinted from the June, 1987 *Zero to Three*.

The *Early Childhood Research Quarterly*, a research journal sponsored by the National Association for the Education of Young Children, will publish an entire issue devoted to the debate of scientific problems associated with the study of infant day care in Spring, 1988. This issue, entitled "Infant Day Care: A Special Issue" and edited by Greta G. Fein and Nathan A. Fox, consists of two parts. The first part includes a detailed review by Jay Belsky of studies examining the impact of early nonmaternal care on infant socio-emotional development. This review is followed by Peer Review Commentaries prepared by Ross Thompson, L. Alan Sroufe, Alison Clark-Stewart, John Richters and Carolyn Zahn-Waxler, who were invited to discuss their views of the facts, interpretations, and implications of this research. The second part of this issue contains six articles that describe empirical studies of infants and parents who have had varying degress of contact with nonmaternal care environments. These studies illustrate efforts to consider quality care, cross-cultural settings, alternative measures of attachment, and, importantly, differences in the families who choose infant care.

For further information, contact Greta Fein, College of Education, University of Maryland, Room 2311, H.R.W. Benjamin Building, College Park, Maryland 20742.

Publications

Risking the Future: Adolescent Sexuality, Pregnancy, and Childbearing, Volume I—Cheryl D. Hayes, editor (Washington, D.C.: National Academy of Sciences, 1986). Available from National Academy Press, 2101 Constitution Avenue, N.W., Washington, DC 20418 for $21.95.

The National Academy of Sciences' Panel on Adolescent Pregnancy and Childbearing was convened to collect, review and evaluate the data on trends in adolescent pregnancy and childbearing and on the antecedents and consequences of this phenomenon. The group was also charged with initiating proposals for the evolution of potentially helpful programs.

After two years of review, analysis and debate, the panel reached six general conclusions:

1. Prevention of adolescent pregnancy should have the highest priority.
2. Sexually active teenagers, both boys and girls, need the ability to avoid pregnancy and the motivation to do so.
3. Society must avoid treating adolescent sexuality as a problem peculiar to teenage girls.
4. There is no single approach or quick fix to solving all the problems of early unintended pregnancy and childbearing . . . adolescents are not a monolithic group.
5. Priority should be given to serving young adolescents and those from the most socially and economically disadvantaged backgrounds.
6. Responsibility for addressing the problems of adolescent pregnancy and childbearing should be shared among individuals, families, voluntary organizations, communities and governments.

Infant-Mother Attachment: The Origins and Developmental Significance of Individual Differences in Strange Situation Behavior—Michael E. Lamb, Ross A. Thompson, William Gardner and Eric Charnow (Hillsdale, New Jersey: Lawrence Erlbaum Associates, 1985). $36.00.

The goal of this volume is to provide a thorough review of the literature concerning the origins, interpretation and developmental significance of individual differences in early infant-parent attachment. More specifically, the authors are concerned with the validity and usefulness of the Ainsworth Strange Situation procedure in assessing the quality or security of infant-parent attachment and its ramifications for later development.

The authors find that "the strong claims regarding the antecedents, interpretation, temporal stability, and predictive validity of Strange Situation behavior are only partly supported by the empirical and theoretical literature." They note that "simply because two infants behave similarly in the Strange Situation, we cannot assume that there have been similarities in their experience with their parents, nor that there will be similarities in their subsequent developmental trajectories . . . The Strange Situation cannot and should not be used as a sole indicator of the quality of parent-child relations."

Several directions for future research on early attachment relationships are identified: conceptualization of attachment; cross-cultural research; and development of continuous measurement systems.

Infant Stimulation: For Whom, What Kind, When and How Much?—Nina Gunzenhauser, editor, with introduction by Barry M. Lester and Edward Tronick (Johnson & Johnson Baby Products Company Pediatric Round Table: 13, 1987). Available from Johnson & Johnson Baby Products Company, Grandview Road, Skillman, NJ 08558 for $9.00.

In this summary of a 1986 Pediatric Round Table, recent research information and ideas about development in preterm infants and the effects of stimulation on their development are critically evaluated by authorities in child development, pediatrics, physiology, animal behavior and neurology. These include Kathryn Barnard, T. Berry Brazelton, Jennifer Buchwald, Cynthia Garcia Coll, Tiffany Field, Joy Goldberger, Peter Gorski, Frances Degen Horowitz, Robert Isaacson, Anneliese Korner, Barry Lester, John Masters, Barry Nurcombe, Arthur Parmelee, Craig Ramey, Michael Schwartz, D. Nico Spinelli, Edward Tronick, Peter Vietze and Doris Welcher. Their papers consider both pre-and normal-term infants from the viewpoints of brain plasticity, appropriate levels of stimulation, development and assessment, and intervention.

The Round Table participants developed a set of nine guidelines for stimulation of preterm infants in special care nurseries from initial admission to hospital discharge. These guidelines stress the need for both interdisciplinary research and training. They emphasize that stimulation of healthy preterm infants approaching term should be related to the developmental level and needs of the individual infant, with physiological homeostasis, control of state organization and engagement with the environment seen as important steps in development. An interdisciplinary "developmental plan" is recommended, to help parents understand the infant's medical and behavioral status, deal with their own feelings, and plan for discharge and follow-up.

Conference Call

January, 1988

January 14-15: *The Mid-Coastal California Perinatal Outreach Program of Stanford University Medical Center* will hold its eighth annual meeting, entitled "Perinatal Potpourri: Reaching Out and Looking Forward," in Monterey, California. A 31-member faculty will address frequently encountered problems in the care of mothers and infants. The program will also offer opportunities to discuss the organization of perinatal care in the mid-coastal region of California. Contact Georgene Jansen, Stanford University Medical Center, 750 Welch Road, Suite 120, Palo Alto, CA 94304, tel: (415) 723-5763.

January 15-17, February 12-14: *Child Development Resources* in Lightfoot, Virginia will sponsor two weekend institutes on early intervention in Williamsburg, Virginia. The January Institute, "Family Systems in Early Intervention," will feature Ann and Rudd Turnbull. William Dyer and Sonja Prestridge will serve as faculty for the February institute, "Building Teams That Work." For more information, contact INSTITUTE, P.O. Box 299, Lightfoot, VA 33090, tel: (804) 565-0303.

February, 1988

February 14-16: *The Infant-Parent Institute* of Champaign, Illinois will hold its fourth annual Winter Advanced Seminar in Infant Mental Health in Grand Rapids, Michigan. Michael Trout, Director of the Infant-Parent Institute, will use video and case studies to illustrate the impact of separation and loss in infancy; infant hospitalization, foster care and adoption; and cases involving termination of parental rights. Enrollment is limited to 20. Contact Michael Trout, Infant-Parent Institute, 501 South Sixth, Champaign, IL 61820, tel: (217) 352-4060.

February 15-26: *The Family Child Learning Center* of Akron, Ohio will sponsor a workshop on "Infant Intervention and Treatment" in Tallmadge, Ohio given by Philippa Campbell and Family Child Learning Staff. For more information, write to Children's Hospital Medical Center of Akron, 281 Locust Street, Akron, OH 44308.

February 29-March 2; March 23-25; April 18-20: *Contemporary Forums* will sponsor conferences on neonatal nursing in San Diego, Boston and New Orleans that will focus on nursing care of the sick neonate. For more information, write or call *Contemporary Forums*, 530 LaGonda Way, Suite E, Danville, CA 94526, tel: (415) 820-2800.

March, 1988

March 10-11: *The Nebraska Symposium on Motivation* will hold its spring session on "Socioemotional Development" at the University of Nebraska-Lincoln. Carolyn Saarni, Carolyn Zahn-Waxler, Grazyna Kochanska and Dante Cicchetti will present papers. For information write to the Nebraska Symposium on Motivation, Department of Psychology, University of Nebraska-Lincoln, Lincoln, NE 68588-0308.

March 18-20; July 15-17: *The International Childbirth Education Association (ICEA)* will hold international conventions in Boston in March and in Honolulu in July. The Boston program will feature sessions on AIDS and the childbearing woman, the role of the doula, and educating pregnant teens, among other topics. For information about the Boston and Honolulu conventions, contact ICEA, P.O. Box 20048, Minneapolis, MN 55420-0048, tel: (612) 854-8660.

March 20-23: *The Greater Cincinnati Hospital Association* and seven other institutions and organizations will sponsor a conference in Cincinnati, Ohio on the aging of children with chronic conditions and disabilities. James M. Perrin will give the opening address. Call or write Vickie Michels, Greater Cincinnati Hospital Council, 1811 Losantiville Avenue, Suite 450, Cincinnati, OH 45237, tel: (513) 531-0200.

March 20-23: *The National Association of Pediatric Nurse Associates and Practitioners* will hold its 9th Annual Nursing Conference on Pediatric Primary Care in Boston, Massachusetts. T. Berry Brazelton will deliver the keynote address, "Advances in Maternal-Infant Care: The Role of the PNP." For more information, contact Anthony J. Jannetti, Inc., Conference Management, North Woodbury Road, Box 56, Pitman, NJ 08071, tel: (609) 589-2319.

April, 1988

April 3-6: The *World Association for Infant Psychiatry and Allied Disciplines*, the *University of Hawaii* and the *University of California, Irvine* will co-sponsor the first Pacific Rim WAIPAD Congress on Infant Psychiatry in Honolulu, Hawaii. The theme of the Congress will be "Transcultural Studies in Infancy." Robert Emde, Joy Osofsky, Eleanor Galenson, Serge Lebovici, Peter De Chateau, Bertrand Cramer, Daniel Stern, Justin Call and E. James Anthony plan to present their most recent work and to offer consultation workshops. For information call or write Justin D. Call, Division of Child and Adolescent Psychiatry, UCI Medical Center, 101 City Drive South, Orange, CA 92668, tel: (714) 634-6023.

April 14-15: *The E. John Gavras Center* will sponsor its eighth Focus on Infants conference in Auburn, New York. Presentations will be given on understanding families of disabled children, the Carolina Curriculum Scale, determining augmentative communication needs, gait analysis, coping strategies in infants, serous otitis media's effect on language development, and posturography and balance. Speakers will include M. Suzanne Hasenstab, G. Gordon Williamson, Marianne Lang, Sally Deitz, Albert Signer and Pat Porter. Contact Focus on Infants Conference Committee, E. John Gavras Center, 182 North Street, Auburn, New York, 13021, tel: (315) 255-2746.

April 22-23: *The Family Child Learning Center* will sponsor a workshop in Akron, Ohio on "Infant Intervention: Roles of Families and Professionals," given by Philippa Campbell and Family Child Learning staff. For more information write to Children's Hospital Medical Center of Akron, 281 Locust Street, Akron, Ohio 44308.

April 25-26: The *Michigan Association for Infant Mental Health* will hold its 12th annual meeting in Ann Arbor, Michigan, focusing on "Collaborating on Behalf of Special Needs Infants and Young Children: Challenges for Practitioners, Educators and Social Policy Makers." For more information, write to Thomas Horner, Child and Adolescent Psychiatric Hospital, University of Michigan Medical Center, Ann Arbor, MI 48109.

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Infants and Toddlers in Hospitals: Adressing Developmental Risks

by
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The Johns Hopkins Hospital Children's Center
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Hospitalization represents one brief segment of some children's early experience; it is a repeated event for others, and becomes a way of life for a few. Of the infants and toddlers who are admitted to hospitals daily, some will have diagnoses that suggest full recovery while others will face chronic or progressive medical conditions. The process of providing essential treatment for these very young children may require simple IV therapy, one or many diagnostic procedures, one or many surgical procedures. During their contact with numerous, ever-changing hospital caregivers, many interactions will involve pain or discomfort, most interactions will be somewhat intrusive, and few will be responsive to the child's own cues. Feeding may be prohibited, severely restricted, or encouraged beyond the child's natural desire to eat. Physical restraint may be necessary for varying periods of time. Discomfort with little relief. Parents may or may not be available.

Surprisingly little attention has been paid to the experience of acutely and chronically ill infants in hospitals, other than those in neonatal intensive care, even though it is estimated that more than half of pediatric in-patient beds are filled by children under 3 years of age (American Academy of Pediatrics, 1986). This article describes the disruptive, chaotic and non-contingent qualities that hospitals share with other high-risk social environments; explores the developmental implications of these circumstances for infants, toddlers and their families; and suggests strategies for care to address the developmental needs of very young children who are hospitalized.

The hospital environment

In examining the social and developmental characteristics that typically accompany even high quality medical care, investigators who have described the chaotic and non-supportive nature of the hospital environment (Goldberger, 1987, and in press; Grant, 1983; Hagemann, 1981a, and 1981b; Jones, 1979; Smith, 1976; Thompson, 1985).

The physical environment is both monotonous and unpredictable. Sensory experience may be fragmented: tube feedings, for example, bypass the normal experience of sucking, swallowing, tasting and physical contact; the sounds of machinery or continuously playing televisions and radios cannot be connected visually to their sources by young infants (Jones, 1979).

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Life sustaining care may involve both pain and unrelenting hunger as a result of restrictions on oral feeding. Infants and toddlers are restrained during medical procedures and to prevent pulling at or exploring medical tubing; they may also be confined in cribs, highchairs and playpens if caregivers are not available to supervise exploratory play.

A large proportion of social interactions in hospitals are non-contingent and intrusive. The large number of frequently changing caregivers may be particularly challenging to very young children. Contingent, responsive care is made less likely by tracheostomies, respirators or the effects of handicapping conditions, which may make language for the young child impossible or difficult to interpret. Particularly for infants and toddlers with chronic conditions who become "favorites" during extended or repeated hospital stays, social interactions are typically highly stimulating, intrusive and sudden, much as are caregiving interventions. With the good intention of eliciting a smile or a cute trick, but often without empathy for the child's emotional or physical experience or developmental needs, numerous loving caregivers may interact briefly and in rapid sequence.

Despite the changes in hospital policy that followed seminal research on the developmental effects of separation and institutional care (Bowlby, 1960; Bowlby, Robertson, and Rosenbluth, 1952; Edelston, 1943; Provence, and Lipton, 1962; Robertson, 1958; Spitz, 1945) prolonged infant-parent separations still occur frequently and are of great concern. How long a separation is too long for a child to tolerate depends on numerous factors. Despite hospital policy that at least formally encourages parents to "live in," lengthy or repeated hospitalizations, parents' work responsibilities, the needs of other chidlren, and lack of adequate transportation may make parents' absence necessary. The quality of interaction between parents and their young child may also suffer during hospitalization. Fear, guilt, grief, depression, exhaustion or inexperience and immaturity may exacerbate parents' emotional unavailability as well as inhibit their physical presence. Professionals eager to teach but not prepared to learn from families may fail to acknowledge parents' expertise and competence (Knapschaefer, 1987; Thomas, 1987). Furthermore, the focus on what is "wrong" with the child, both medically and developmentally, may result in inadequate attention to the child's strengths and areas of health. Professionals may contribute to what Green and Solnit (1964) described as the "vulnerable child syndrome," in which some parents persist to a pathological degree in perceiving of their child as sickly or vulnerable following an illness in infancy or todderlhood, despite a full and satisfactory recovery.

Behavior of hospitalized infants and toddlers

Infants and toddlers who experience lengthy or repeated hospitalization often demonstrate certain behavioral qualities. These may include:

- social and exploratory passivity;
- an inhibited perception of their ability to move beyond immediate physical space (e.g., reaching for a toy requiring a slight stretch from a stable sitting position, or crawling once a quadruped position can be sustained);

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- a narrow range of affective expression that may be limited to irritability or, just as likely, to the consistently jovial behavior that is reinforced by staff;
- distractibility;
- disinterest in fine motor tasks that require eye-hand coordination, and preference for a limited repertoire of gross motor schemata that allow the child to wave, bang, shake and mouth toys while visually scanning the environment;
- persistent mouthing of toys despite developmental maturity that would suggest the decrease or elimination of this form of exploration (particularly notable in infants and toddlers with tracheostomies, even if receiving oral nutrition, and in those who do not receive a significant portion of their nutrition orally); and
- notably minimal vocalizations and few attempts at intentional verbal communication.

The long-term developmental effects of hospitalization during infancy and toddlerhood have been explored by Douglas (1975), Dowling (1977), Quinton and Rutter (1976), Schaffer and Callender (1979), McDonald (1981) and Meijer (1985). The complex interactions that occur between the hospitalized infant and the caregiving environment may best be illustrated by several case examples from a pediatric tertiary care center.

Shantal, now four months old, was born more than 10 weeks prematurely to a drug-abusing mother from whom she inherited both HIV antibodies and cytomegalovirus. She has a tracheostomy and bronchopulmonary dysplasia remaining from her extended requirement for a respirator. She may or may not develop symptoms of AIDS, but she is becoming medically stable.

Shantal's mother is increasingly ill, and no other family members visit the child. Despite the affection shown Shantal by her primary nurses, often no one is available to interact with her and optimize her experience during her brief naturally occurring awake and alert times. Since hospital policy requires her isolation from other patients, Shantal cannot even watch the pleasurable activity of the playroom. Finding a foster home is a challenge.

Frank developed necrotizing enterocolitis soon after birth, and has required significant and repeated abdominal surgery plus additional surgical procedures for placement of special intravenous catheters to enable the provision of total intravenous nutrition. In the six months of his life he has not had a single oral feeding. His parents visit each evening, but must work in the daytime to maintain their modest income and insurance coverage. As a result, Frank stays awake late at night but is sleepy during the day when nurses, physicians, therapists and nutritionists must evaluate his progress and provide their interventions. When they awaken Frank, these professionals may offer reasons: "He shouldn't be asleep at this time of day;" "He probably just fell asleep;" "He will probably wake up soon anyway;" "He won't mind;" and "It would be hard for me to come back to this unit later." Sometimes Frank is irritable. Some professionals consider him "lazy" or "spoiled."

Jasmine is now 14 months old and has been on our unit her entire life. Her prognosis is guarded, and she will likely be on our unit for many more months. She too has never received oral nutrition. Each nurse, doctor, housekeeper, therapist, parent, and transport aid who has ever had contact with Jasmine is drawn to her smiles and "cute" responses. As each one passes her room, he or she calls out an affectionate greeting or stops for a quick hug or tickle. Jasmine smiles, calls back some enchanting response, and continues to play, never once looking at her hands and always scanning the hall for the next "friend." Each passerby loves her in his own way, and eagerly accepts Jasmine's generous social rewards. Jasmine gives people pleasure in their day. Some of these friends are known to give her secret licks of lollipops and other tastes, although her sensitive gut will not tolerate even slow, tiny drops of Pedialyte given through her gastrostomy tube. Her father, who has returned to his native country, would prefer her mother not to be involved with this sick female infant, who has many strikes against her according to their cultural and religious values. So family rarely visits Jasmine, and nurses love her as their own.

Sandi is particularly worrisome. She is a five month old, now hospitalized for the second of what will probably be many hospital admissions. She has significant orthopedic and neurological anomalies, and is failing to thrive despite much medical intervention. Sandi will have several persisting areas of handicap despite intellectual capacity that seems within normal limits.

Sandi's mother has a three-year-old to care for, but travels nearly an hour each way three or four times per week as often as her own mother can babysit to visit for several hours. Sandi's father is increasingly backing off and the marriage is increasingly rocky. Mom seems to be a real fighter, a devoted mother who will find a way for Sandi, and a way for herself, too, if need be.

When her mom has been with her Sandi has enough energy to look around the room and smile spontaneously at a very few familiar faces, and to reach for lightweight toys. Sometimes she even coos. But the therapist who visits in the morning, when mommy is never there, doesn't get to see this. She sees Sandi as irritable (which she is). Right now Sandi is not eating by mouth. She is ravenously hungry and somewhat hard to console. She gets her primary comfort from sucking vigorously on her pacifier. She tends to turn away from caregivers, and sometimes looks rather limp and dazed when she is held. So Sandi is not a favorite, and does not have, like her roommate Jasmine, a long line of people eager to nurture her.

Strategies for care

In this writer's experience the developmentally worrisome behaviors of hospitalized infants and toddlers are largely eliminated as significant problems when parents persist in providing daily, mutually gratifying interaction. Thus the foremost goal of psychosocial services to families should be encouraging parents' positive perception of their infants and involvement in their daily care. Unfortunately, as this is often not possible, professioanl staff must take special pains to address and to compensate for the effects of medical treatment.

One avenue of support for the development of hospitalized young children is through coordinated interdisciplinary care. "Interdisciplinary" is a hospital catchword of the 1980s. It often seems that the more consultants involved, the more people feel that the hospital is "doing something" for a child. However, interdisciplinary care can sometimes mean too many strangers to whom the infant must adapt or respond; too many strangers giving parents information or advice, or competing for the child's attention; days organized to fit caregivers' schedules rather than the infant's rhythms and patterns; and overwhelming, ever-changing numbers of caregivers, whose agendas may be in competition with sick infants' needs for attachment, rhythm predictability, intrinsic motivation, and emerging independence.

Genuinely interdisciplinary care should be noncompetitive with parents; should encourage parents' role as the ultimate coordinators of the team on behalf of their child; should reinforce parents' perception of their infant's areas of health as well as ilness; and should also reinforce parents' perception of their own strengths. Nursing, child life and rehabilitation therapies should enhance the infant's emerging capacities for rhythmicity, attachment, pleasure, and self-motivated and successful activity, and balance predictable daily patterns with interesting novel events. Optimal interdisciplinary care should be carried out through consistent care patterns performed by as few, rather than as many, different professionals as possible. Staff should be educated to engage in responsive, interactive social play rather than intrusive, interrupting play.

In addition, play can address emotional or developmental needs both preventively and remedially (Goldberger, 1988). Play can be used *preventively* to facilitate enjoyable parent-infant interaction, to aid parents in perceiving their infant's capabilities, to provide developmentally appropriate opportunities, and to structure time in order to both minimize stressful or fearful anticipation and provide normalizing experiences. Preventinve play might include planning a child's care and medication to be grouped together to provide long, uninterrupted blocks of time for play and naptime. A three month old requiring arm restraints for example, could then be supervised in a play setting without restraints and with ample opportunity for reaching and grasping; a child life specialist or nurse might facilitate hiding and finding games for a toddler prior to a parent's departure. Play can be provided *remedially* to aid in establishing predictable, enjoyable rhythmic patterns; to address problems created by the medical environment, such as passivity, incorporation of medical equipment in body

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image, channelling anger and frustration; and to provide preparation and desensitization for medical and surgical experiences. A very few examples of remedial play might include directed throwing games to reduce tension in confined toddlers, doll play with medical tubing and familiar equipment specific to a child's medical experience, and use of mirrors and stroking to aid children in acquainting themselves with the parts of their body obscured by medical equipment (for example infants on respirators may not be able to see their feet, or even hands, in order to begin to reach for and explore them.

Let us now return to Shantal, Frank, Jasmine, and Sandi to see how we might be able to enhance their care.

Shantal. Our hospitals are filling with Shantals. We need to recall the insights of Spitz (1945), and of Provence and Lipton (1962), concerning the grim prognosis for infants and toddlers who receive adequate or excellent physical care in the absence of adequate emotional nurturing. Shantal needs consistent caregivers to enjoy her and to delight in her achievements. While she awaits a foster home, primary nursing and child life care can help Shantal to establish relationships and maximize her still brief periods of alert attention. Because stringent cost-containment polices have staff stretched to their limit, with too little time remaining for truly adequate attention to Shantal's social and emotional needs, a foster grandparent program could help greatly, although legal questions regarding confidentiality of patient diagnoses along with volunteer's rights to make an informed choice regarding contact with patients who test positively for AIDS antibodies complicate that solution. Policies encouraging more generous staff-to-patient ratios for children in isolation would be ideal.

The Child Life Specialist

A Child Life Specialist is a professional who focuses on the emotional and developmental needs of children in the context of health care. Although most Child Life programs are hospital-based, Child Life Specialists work in all health care settings. In community hospitals a single Child Life Specialist may serve all pediatric patients; in larger tertiary care centers, Child Life professionals may work only with children within a specific age range or within a diagnostic subspecialty.

To be certified, Child Life Specialists must have at least a bachelor's degree in education, early childhood, psychology, family studies, or another related discipline; must have completed an internship in Child Life: and must have completed six months paid experience in the field. Specific Child Life training is available through colleges, universities, and internship programs.

The Child Life Council, which has been organized to address professional issues, operates under the umbrella of the Association of the Care of Children's Health (ACCH), a multidisciplinary organization devoted to humanistic issues of children and families in health care settings. The Child Life Council and ACCH jointly sponsor an annual conference, and ACCH publishes *Children's Health Care,* a quarterly journal which disseminates research and clinical experience in psychosocial issues in pediatric health care.

Further information is available from the Child Life Council or ACCH at 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016, tel.: (202) 244-1801.

Frank. A care plan that follows Frank's sleep and waking patterns would be likely to maximize his interest and performance, and to increase the mutual enjoyment and gratification of child and staff in interaction. Several times daily, and ideally as often as his parents would like, the experience of feeding in an age-appropriate manner should be imitated as closely as possible. Even a few milliliters of Pedialyte could continue oral experience and sucking and swallowing, as could holding, cuddling and encouraging Frank to suck on a pacifier with a nipple whose shape is the same as the nipple that will be used for feeding. Again, precious staff time should ideally be used to provide such normalizing experiences in addition to essential medical care.

Jasmine. Pediatrician Arthur Parmelee (cited in Goldberger, 1987) requires that his staff interact with a hospitalized infant or toddler for at least 15 minutes; if staff can't spend that much time, they must come back when they can. Such a rule would be a creative solution to the innumerable, intrusive and overstimulating brief interactions imposed on "favorite" patients such as Jasmine. With her medical complications, Jasmine could have been identified soon after birth as at risk for extreme lack of oral experience, extreme learned passivity, daily challenges to her ability to learn to concentrate, and impoverished language opportunities. There is little we could do to prevent the consequences of repeated surgical procedures, which seem to occur just when she has become interested in or begun to master a new skill, and causing her to need to begin afresh after each surgery. We might concentrate on alternate ways of reaching beyond her immediate sphere and her motivation to be an active, problem-solving participant rather than a passive recipient of developmental stimulation. Toys with high rewards might facilitate this interest, but, again, responding contingently to her cues and behaviors would be an even more significant focus. Perhaps someone other than hospital staff might reach her parents more satisfactorily, such as a religious leader who might support their increased involvement. If not, better education and emotional support for staff might help staff channel their anger and frustration at Jasmine's family's infrequent visits, and gain respect and understanding of their fears, inexperience, beliefs and cultural differences that are influencing their behavior.

Sandi. Even were she healthy, Sandi would probably be emotionally fragile. She is at her best when her mother is available: what can we do to maximize her mother's ability to be present? Hospital-based day care for siblings? Counseling to address the family's increasing tension, which is often focused on whether or not Sandi should come home or be included in family holiday events? A parent support network that encourages parents of children and similar handicapping conditions to encourage and learn from each other?

Sandi is beginning to enjoy social contact, particularly from a distance and if touching is not involved. At those times when Sandi is offered oral feedings, she will drink while she is being held by the few people who enjoy caring for her; she will refuse feedings, no matter how hungry she seems, when they are offered by someone who does not enjoy caring for her. It should become part of her primary nurses' and child life care plans to respect Sandi's comfort level as much as possible, and move toward her slowly. Recently she has begun to tolerate a caregiver sitting next to her without her looking away. Even though she may not look at a favored caregiver, she least may not appear pale and limp when her arms are stroked. Cute clothes may help staff feel attracted to this infant, who is minimally interested in people and who is not enjoyed by most hospital staff.

Not long ago, a caring therapist expressed concern that when she tried to interact with Sandi after therapy, the infant did not visually track either her or a toy nor did she turn to sound. (At that moment, in fact, Sandi was using her energy to search for her pacifier which she could not successfully maneuver to her mouth because of the IV in her arm.) It was a new idea to this very kind, very concerned therapist (and to the student who wanted to try a black-and-white stimulation kit to improve Sandi's visual tracking) that Sandi might not be watching them because she was too tired, hungry, stressed, and probably hurting to reach beyond whatever small, but predictable, comforts she could provide herself. It was new for the therapist to think of motor skills as so closely linked with emotional response.

Now Sandi *is* capable of and interested in reaching and grasping toys. We must provide opportunities with adequate complexity, variety, satisfaction, and interest, along with caregiving so that she will learn to enjoy people, to be interested in the world, to concentrate, and to pursue her own goals even in the hospital environment.

Conclusion

In these days of rapidly advancing medical technology and decreasing availability of and priority to psychosocial services, it will be a challenge to match the quality of emotional care to the quality of technical care. In addition, parameters for optimally supportive care for infants and toddlers in hospitals need further definition and demonstration. Staffing and services should aim to reflect more attention to quality of life rather than short-sighted financial constraints, and those responsible for the delivery of care should strive to understand infants' priorities and make them their own.

Bibliography

American Academy of Pediatrics Committee on Hospital Care (1986), *Hospital care of children and youth.* Evanston, IL: Academy of Pediatrics.

Bauman, S. (1981), Physical aspects of the self. *Psychiatric Clinics of North America,* 4(3): 455-470.

Bowlby, J. (1960), Separation anxiety. *International Journal of Psycho-Analysis, 41* (2-3): 89-113.

Bowlby, J., Robertson, J., & Rosenbluth, D. (1952), A two-year-old goes to the hospital. *Psychoanalytic study of the child. 7:* 82-94.

Douglas, J. (1975), Early hospital admissions and later disturbances of behavior and learning. *Developmental Medicine and Child Neurology, 17:* 456-480.

Dowling, S. (1977), Seven infants with esophageal atresia: A developmental study. *The Psychoanalytic Study of the Child, Vol. 32,* New Haven, CT: Yale University Press.

Edelston, H. (1943), Separation anxiety in young children: A study of hospital cases. *Genetic Psychology Monographs, 28:* 3-95.

Goldberger, J. (1987), Infants on acute care hospital units: Issues in stimulation and intervention. In: B. Lester & E. Tronick (Eds.) *Pediatric round table 13: Infant stimulation* (pp. 111-121). Skillman, NJ: Johnson & Johnson Baby Products.

Goldberger, J. (1988), Issue-specific play with infants and toddlers in hospitals: Rationale and intervention. *Children's Health Care: Journal of the Association for the Care of Children's Health, 16,* (3): 134-141.

Goldberger, J. (in press), Supportive environments for infants and toddlers in hospitals: What we know, where we are heading, and where we should aim to be. *Children's Environments Quarterly.*

Grant, V. (1983), Pedestrian traffic in a paediatric ward. New Zealand Medical Journal, 96: 91-93.

Green, M., & Solnit, A. (1964), Reactions to the threatened loss of a child: A vulnerable child syndrome. *Pediatrics, 34:* 58-66.

Hagemann, V. (1981a), Night sleep of children in a hospital, part I: Sleep duration. *Maternal-Child Nursing Journal, 10:* 1-13.

Hagemann, V. (1981b), Night sleep of children in a hospital, part II: Sleep disruption. *Maternal-Child Nursing Journal, 10:* 127-142.

Jones, C. (1979), Criteria for evaluating infant environments in hospitals. *Children's Health Care: Journal of the Association for the Care of Children's Health, 7:* 3-11.

Knapschaefer, J. (1987, Dec.), "Whose child is it anyway: Supporting development of young children with chronic illness & their families." Paper presented at National Center for Clinical Infant Programs' Fifth Biennial National Training Institute; Washington, D.C.

McDonald, M. (1981), Alternative treatment of a young boy with a traumatic psychosis: The rediscovery and reconstitution of the self. *Psychiatric Clinics of North America,* 4(3): 509-532.

Meijer, A. (1985), Hospitalization as a long-term at-risk indicator. In: S. Harel & N. Anastasiow (Eds.), *The At-Risk Infant: Psycho/Socio/Medical Aspects* (pp. 275-284). Baltimore: Brookes.

Provence, S., & Lipton, R. (1962), *Infants in institutions.* New York, International Universities Press.

Quinton, D., & Rutter, M. (1976), Early hospital admissions and later disturbances of behavior: An attempted replication of Douglas' findings. *Developmental Medicine and Child Neurology, 18:* 447-459.

Robertson, J. (1958), *Young Children in Hospitals.* New York: Basic Books.

Schaffer, H., & Callender, W. (1979), Psychologic effects of hospitalization in infancy. *Pediatrics, 24:* 528-539.

Smith, J. (1976), Spending time with hospitalized children. *MCN: American Journal of Maternal Child Nursing, 1:* 164.

Spitz, R. (1945),, Hospitalism: An inquiry into the genesis of psychiatric conditions in early childhood. *Psychoanalytic Study of the Child, Vol. 1:* 53-74.

Tamaroff, M., Nir, Y., & Straker, N. (1986), Children reared in reverse isolation: Effects on cognitive and emotional development. *Journal of Autism and Developmental Disorders, 16:* 415-424.

Thomas, R. (1987, Dec.), "Whose child is it anyway: Supporting development of young children with chronic illness & their families." Paper presented at National Center for Clinical Infant Program's Fifth Biennial National Training Institute, Washington, D.C.

Thompson, R. (1985), *Psychosocial Research on Pediatric Hospitalization and Health Care.* Springfield, IL: Thomas.

Preparing Pediatric Residents for the Primary Care of Children with Chronic Illness and Their Families: The Chronic Illness Teaching Program

by
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Since 1984, more than two dozen pediatric residents have participated in a unique three-year training program associated with Michigan State University, the Chronic Illness Teaching Program. This program was initiated with the goal of helping future pediatricians to develop the knowledge, skills and attitudes they need to assume the complex role of health care provider for infants and children with chronic illness or disability. This article describes the needs that led to the development of the teaching program, the approaches that we have used during the past three years, and insights that may prove useful to other parents and professionals.

The need for specially trained primary care providers

Chronic medical conditions affect 10% to 20% of all children (Gortmaker and Sappenfield, 1984). The impact of a chronic illness or disability can be pervasive, on both child and family. The specific diagnosis is often less important than the effects of the chronic nature of the condition: any family raising a child with a chronic medical condition may confront the need to use many and varied health and rehabilitative services; ongoing interaction with complex health, financial and education systems; a need for accurate information about the child's special health care needs; demands to make complicated decisions about the child's care; and potential continuing, prolonged stress, with possibly disruptive social and psychological impact on any and all family members, and on the family unit as a whole. Unfortunately, many families may find that *no one* in the health care system is available to help them with advice, counseling, future planning or support (Kanthor, and Pless, 1974).

While primary care pediatricians, working in cooperation with appropriate subspecialists and other health care providers, may be the professionals best situated to assume responsibility for the general management of a child's chronic illness and its impact, evidence suggests that pediatric residents are not being prepared to assist families to receive the education, coordination of services, advocacy, continuity of care, counseling and help with future planning that families and children require (Stein, and Jessop, 1984; Stein, Jessop, and Ireys, 1983; McInerny, 1984). In 1979, the Task Force on Pediatric Education identified the care of children with chronic conditions as a neglected area in pediatric residency training. Five years later, a survey of third year pediatric residents in four training programs found that one-half of these future pediatricians had never cared for a seriously chronically ill child for as long as six months during their entire residency (Sack, WH, Fritz G., Krener D CO, etal, 1984).

JOHN DAVID ARMS

Goals of the Chronic Illness Teaching Program

The creation of the Chronic Illness Teaching Program was based on three premises:

- that, as a group, children with chronic illness and their families may have significant unmet needs;
- that, in general, this area of pediatric education has not been developed; and
- that in the future, the care of children with chronic conditions is likely to occur increasingly in ambulatory and home care settings and to require an increasing share of the resources of pediatricians.

Focusing on the general impact of chronic illness on children and their families, the teaching program complements the disease specific emphasis of subspecialty inpatient and ambulatory training experiences. It prepares the resident to assume five roles in the care of children with chronic illness: 1) provider of continuity of care; 2) coordinator of care; 3) educator; 4) advocate; and 5) counselor.

It should be noted that both attitudinal and structural characteristics of residency education as it currently exists can serve as potential barriers to preparing pediatricians to be effective in these roles. Several common **attitudes** may serve as barriers:

- "Cure" may be seen as the only measure of a physician's success; when in fact it is improvement or stabilization of function that may mark genuinely successful care for this group of children;
- A perception of chronic illness as the sole domain of subspecialists may result in de-emphasis of the primary care role; and
- The view that physicians are the sole or best source of knowledge and care ignores the significant contribution other professionals can make and greatly increases the burden of the management of complex care on the physician. This attitude may also discourage families from developing their own management skills.

Structural characteristics common to many residency programs may serve as barriers to teaching about chronic illness:

- Short, episodic clinical experiences provide few opportunities for continuing involvement with this group of children and families;
- Emphasis on inpatient experiences may fail to prepare the resident adequately for ambulatory and home care, and the lack of appropriate training sites makes teaching about respite and hospice care difficult.
- Few opportunities to coordinate complex care may limit the resident's ability and willingness to provide coordination services once he or she enters practice.
- Teaching an integrated approach to chronic illness care requires faculty who are prepared and willing to serve as role models to pediatricians in training and to pursue research questions related to the care of children and families facing chronic illness.

The Chronic Illness Teaching Program was designed to overcome these potential barriers. The specific objectives for the pediatric resident are: 1) to obtain an understanding of the impact of chronic illness on the child, the family, the professional service providers and society; 2) to acquire specific primary care skills necessary for the care of these children; 3) to understand the process of coordinating care with the family and with other health, education and service professionals; 4) to develop attitudes and values associated with patient/family autonomy; and 5) to evaluate success based on improvement of function rather than cure.

The program spans three residency years and has four major components: **family studies, services for children with chronic illness, knowledge and skills, and issues in chronic illness.** These areas are the structure for all three one-month block rotations; different activities in each area occur in the three training years. Information regarding the curriculum structure appears in Tables 1 and 2.

The central focus and most successful element of the program is the area of **family studies.** Each resident undertakes two three-year studies: the Longitudinal Family Study and the Clinical Case Review. The purpose of the Longitudinal Family Study is to provide the resident with ongoing exposure to the general social, financial, educational, and psychological effects of chronic illness on the child and family. The resident conducts at least one home interview with the family each year in order to learn about the positive and negative impact of chronic illness or disability over time. The resident is also encouraged to accompany the family during a health or social service visit, to observe the child at school, and to interview other professionals about their contribution to the child's care. Most residents produce a video or audio tape of the home interview(s) which is reviewed with the faculty with regard to both content and the resident's interactional skills. The resident also reviews the literature regarding one or more issues presented by the family, and presents the family study at a faculty conference at the end of each yearly rotation. This process culminates in a final presentation which summarizes what has been learned during three years of contact with the family. Examples of topics chosen by residents for indepth study have included organization of home care for an infant requiring ventilator support; the impact of the death of a severely impaired infant on the family; and attitudes of a single, teenage mother about the role of numerous "helping professionals" in the care of her infant with congenital heart disease.

Table 1: First Year Block Rotation Curriculum Structure (one month)

The Family Studies	
The Longitudinal Family Study	
Family Interviews	*
Literature Review	*
Presentation to Faculty	2½ hrs
The Clinical Case Review	
Medical Record Review	*
Case Review with Faculty	2 hrs
Services For Children with Chronic Illness	
Continuity Clinic	4 hrs/week
Home Care Visit with Visiting Nurse	1 or 2 days
Cleft Palate Clinic	½ day
Central Diagnostic Team Intermediate Schools	½ day
Regional Center for Developmental Disabilities (Residential Care)	1 day
Optional Additional Agency Visits:	*
School Visits (Schools of children in case studies)	*
Knowledge and Skills and Chronic Illness Issues	
Literature Review	*
The Chronic Illness Teaching Conference	2 hrs/wk
Discussions with Faculty (2 sessions/week minimum)	4hrs/week**

*Arranged by Resident **Additional Contact by Arrangement

Table 2: Curriculum Structure

Topic Area/Method	Year I	Year II	Year III
FAMILY STUDIES			
Longitudinal Family Study (Home Interview)	General Impact of Chronic Illness	Effects on Child Development Family System	Pediatrician Role Effects of Social Policy Decisions
Clinical Case Review	Case Management Review I	Case Management Review II	Case Management Review III
SERVICES			
Site Visits and Clinical Experiences	Home Care Multiprofessional Teams Residential Care	Multiprofessional Teams Neonatal Follow-up Hospice Care	Multiprofessional Teams Private/Prepaid Medical Care
KNOWLEDGE/SKILLS			
Didactic and Clinical Experiences	Interviewing Skills Health Maintenance Home Care Guidelines	Child Development Family Systems Home Care Guidelines	Nutrition Pain Control Home Care Guidelines
C.I. ISSUES			
Didactic Experiences	Improved Function vs Cure	Bioethical Aspects Death and Dying	Pediatrician Role Social Policy Decisionmaking

The purpose of the second continuing study, the Clinical Case Review, is the development of skills in the longitudinal care of a child with chronic conditions. During the first year rotation, the resident and a faculty member conduct an intensive multisystem review of the resident's primary care of a child with chronic illness. The resident reviews the available data, identifies areas of missing information, analyzes the care provided and its outcomes, and constructs a plan for future care based on an assessment of the goals of the resident, the child and the family. This process is repeated during each Chronic Illness Rotation in an attempt to assist the resident to develop a model for ongoing comprehensive case review applicable to the care of any child with a chronic condition.

In the second major topic area, **services for children with chronic illness,** the activities produce familiarity with several aspects of service systems:

- the positive and negative aspects of various models for service delivery;
- the nature of the variety of services available for this group of children; and
- the skills and viewpoints of various health, social service, and educational professionals with whom the physician can work to facilitate optimal outcomes. For example, during the first year rotation, one day is spent with a visiting nurse going to the homes of children with chronic illnesses; the resident simultaneously observes the coordination and management of home care and the role of the visiting nurse. A day with a staff pediatrician at a residential institution for the profoundly physically and developmentally disabled provides information about the social and financial impact of institutional placement on the child, the family and society, as well as the general nature of such facilities. Experience with a multi-professional 'team' model for the care of children with chronic conditions is gained at a multiprofessional cleft palate clinic. The resident observes this model from the perspective of both the family and the professionals by accompanying two families through the clinic and attending the team evaluation/recommendation meeting at the conclusion. Depending on the resident's area of interest, he or she may visit other community services as well. The second and third years provide experience with additional community resources, and all residents are encouraged to participate in a summer camp for children with chronic illness.

The **knowledge and skills** topic area is designed to increase the residents' ability to care for children with chronic conditions. The first year curriculum concentrates on interviewing skills and health maintenance activities, including the development of a health supervision plan for the child presented in the Clinical Case review; the second year focus is on child development and family systems as influenced by chronic illness; and the third year curriculum stresses nutrition management and pain control techniques. Teaching methods include both didactic sessions with the faculty and direct clinical experiences. To develop some familiarity with the increasingly important area of home care, each year the resident constructs guidelines for some aspect of the home care of a particular chronic condition such as chronic renal disease. The resident learns about the home care of three different conditions in the cource of the program.

The final area of study increases the residents understanding of **chronic illness issues.** The first year focus is on improved function as a desirable outcome in chronic illness and the impact of social policy decisions on children and families. The second year emphasis is on bioethical aspects of chronic illness care and issues in death and dying. Third year residents consider the financial aspects of chronic illness care, the social policy decisionmaking process, and the role of the pediatrician. The Longitudinal Family Study is the vehicle for exploring financial issues; the resident identifies the approximate cost of the child's illness to the family and, if possible, to third party payors. Through direct experiences with a state legislator, the resident traces the course of a piece of child-or-family related legislation. The purpose of this activity is not to create medical lobbyists, but to allow residents to understand how such legislation is created and where they might have influence on a particular issue, should they choose to do so. We feel that since the effect of government policies on medical care and practice has become increasingly significant, especially in the area of chronic illness care, these learning opportunities are a critical area of training.

Insights from our experience

The Chronic Illness Teaching Program is now four years old. Each year since 1984, six first year residents have been added to the program. The first group to complete the full three-year sequence graduated in June,

1987. When the first 13 residents who completed the first-year program were asked how likely they were to care for children with chronic medical conditions as practicing pediatricians, eight of the 11 respondents said that as a result of the teaching program, they were more likely to choose to provide care for this group of children. One respondent was less likely, and two reported no change in attitude.

As we consider our experience with the Chronic Illness Teaching Program, three factors appear to be important to its success in our setting.

- First is the creation of "protected time" for the residents during the chronic illness rotation. Initially residents had inpatient night call every fourth night. When this was changed to assignment to an evening clinic with community pediatricians, the flexibility required by the program was enhanced.
- Second is a structure which allows each resident to study an area in the field of chronic illness or disability of particular interest to him or her. This opportunity seems to activate residents to become thoroughly involved with their chosen area of study.
- Third is the requirement that the resident spend time with a family, on a continuing basis, on the family's turf, their home, away from the medical setting and the issues of control which pervade it. During three years of this kind of contact, residents become deeply interested in the family's experiences and progress. In four years only two families refused to be interviewed. The families have been enthusiastic, articulate and anxious for others to learn from their experiences.

We feel that a curriculum like ours could be adapted to fit the circumstances of most other training sites, given appropriate resources. Such resources include:

- Faculty who are prepared and willing to teach about the primary care aspects of chronic illness care;
- Opportunities for residents to gain experience with the management of infants and children with chronic conditions and their families for extended periods of time;
- Training sites at which residents can acquire skills in respite, hospice and home care management; and
- Financial resources to support educational experiences and programs concerning chronic illness and disability.

We believe that through the Chronic Illness Teaching Program our residents develop a comprehensive view of what chronic illness or disability in childhood means to the child, to the family, to community resources and health care providers and to society. They also learn what tangible help pediatricians have to offer these children and families. We have observed that during their three years of training, residents develop increased compassion for the child and family's situation and profound respect for the remarkable capabilities shown by many families in caring for their children with chronic conditions. The creators and multidisciplinary faculty of the Teaching Program have been privileged to learn about these things with our residents, as we continue to look for ways to help future pediatricians assist children with chronic illness to reach their full potential as members of society.

References and bibliography

Arthur, R. and Yager, J. "Future Work Conditions for Physicians: Implications for Medical Education", The Pharos, Summer, 1984.

Desguin, B. Chronic Illness in Children; An Educational Program for a Primary-Care Pediatric Residency. The American Journal of Diseases of Children, 1986; 140:1246-49.

Gortmaker S., & Sappenfield W. Chronic Childhood Disorders: Prevalence and Impact, *Pediatric Clinics of North America*, 1984.

Hobbs N. et al. Chronically Ill Children in America, Rehabilitation Literature, 1985; 45:206-213.

Hobbs N. et al: Issues in the Care of Children with Chronic Illness, Josse-Bass, San Francisco, 1985.

Hoekelman R., Klein, M., and Strain, J. "Who Should Provide Primary Health Care to Children: Pediatricians or Family Medicine Physicians?" Pediatrics, Vol. 74, #4, October, 1984.

Kanthor H. et al. Areas of Responsibility in the Health Care of Multiply Handicapped Children, Pediatrics, 1974; 54:779-785.

Mattson, Ake. "Long Term Physical Illness in Childhood: A Challenge to Psychosocial Adaptation", Pediatrics, Vol. 50, No. 5, November, 1972.

McInerny T.: Role of the General Pediatrician in Coordinating the Care of Children with Chronic ILlness, Pediatric Clinics of North America, 1984; 31:199-210.

Pless I.B. et al. Division, Duplication and Neglect: Patterns of Care for Children with Chronic Disorders, Child Care Health Delivery, 1978; 4:9.

Rogers, D., Blendon, R. and Hearn, R. Some Observations on Pediatrics: Its Past, Present and Future, Pediatrics Supplement, Vol. 67, #5, Part 2, May 1981.

Sack W. et al: Death and the Pediatric House Officer Revisited. Pediatrics, 1984; 73:676-681.

Stein R. & Jessop D.: General Issues in the Care of Child with Chronic Physical Conditions, Pediatric Clinics of North America, 1984; 31:189-190.

Stein R., Jessop D. & Ireys H.: Education of Pediatricians for the Ongoing Care of Children with Special Health Needs. Conference Report, Arden House, 1983.

Task Force on Pediatric Education. The Future of Pediatric Education, Evanston, IL, 1979.

Copies of **"Because Our Babies Are Our Future,"** *the 16-minute videotape produced to celebrate the tenth anniversary of the National Center for Clinical Infant Programs, are available for our cost of $7.50 from NCCIP, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005. The tape highlights research, service and social policy issues concerning infants, toddlers and their families and documents the accomplishments of NCCIP in its first ten years.*

Issues of Infants with a Chronic Illness: A Case Study

by

Lucila Nerenberg, M.D.

Dedicated to the memory of a dear friend, Anita D. Baxter

The writer is in the second year of Pediatric Residency at Michigan State University. The residency training program includes a yearly Chronic Illness Rotation, as described by Barbara Desguin. One aspect of each rotation involves interviewing and videotaping a family with a child with a chronic illness in their home. The resident interviews the same family at yearly intervals so that an ongoing view of both the child and family's experience and environment can be obtained and analyzed as changes occur. The interviews are designed as learning experiences for pediatric residents; no medical advice is offered to the family.

Contact with this family was established and interviews done when Matthew was four and then nine months old. Additional information was obtained by reviewing charts and by conversing with the visiting nurse, social worker and nephrologist involved with the family. Remarks by the family that appear in quotation marks are in paraphrased form. The family was very receptive to the interviews and agreed to the publication of this article for educational purposes.

Family background

The family consists of the mother, father and their sons Timmy and Matthew. This is the father's second marriage. The family lives in the suburbs of a small city; the father's three adolescent sons by his first wife live across the street. The hospital, as well as medical supply outlets are 30 minutes away. Both parents are middle class, educated and hold full-time jobs. They are both in their thirties.

They are active members of their church. The extended family includes both father and mother's numerous siblings, several of whom live nearby. Both sets of grandparents live out of state.

Prior to Matthew's birth, the family's lifestyle was "always very independent; after Timmy was born we took him along camping and to the cabin or out of state. We decided to have only one more child, so we could keep some freedom." When Timmy was two, his mother became pregnant again after two prior miscarriages. She had routine prenatal care and experienced no cause for concern. As the due-date approached mother planned to train a substitute secretary and take several weeks of maternity leave.

Matthew's birth

Matthew was born after a premature labor which began 4 weeks prior to the due-date. Severe fetal distress prompted an emergency cesarean section. Because of continuing severe problems he required resuscitation and immediate transport to the Neonatal Intensive Care Unit (NICU). His condition indicated that he had suffered a lack of oxygen. His nine pound birth weight was abnormally high for his gestational age; this was due to retention of fluid in every system for unknown reasons.

Initially, all of his body systems were compromised. Cardiac failure, kidney failure, acidosis and multiple areas of internal bleeding were all potentially fatal conditions. His lungs required a few days of mechanical ventilation, and chest tubes for the drainage of fluid and the correction of an air leak were needed. Early liver damage was transitory. Tests of his brain revealed signs of a moderate amount of bleeding which later appeared to resolve.

> *The neonatologists explained the severity of Matthew's condition and the probable poor outcome. Both parents insisted, "We want everything done."*

After several days in critical condition, Matthew improved. It appeared he would survive and within weeks almost all of his systems appeared to have recovered their functions. The only irreversibly damaged organs were his kidneys; he never urinated, and fluid and toxic substances accumulated in his already swollen body. A permanent tube was surgically inserted into his abdomen and peritoneal dialysis was begun to substitute for his missing renal function. This was successful, and after sixteen weeks in the NICU, Matthew was discharged to his home. His home care was to include CAPD (continuous ambulatory peritoneal dialysis). He was to be fed by mouth and also by a tube extending from his nose to his stomach. These procedures were to be carried out by the parents.

Coping in the NICU

Chodoff, Friedman, and Hamburg (1964) describe coping as a strategy to deal with a significant threat to one's psychological stability. He divides needs into external and internal; external needs include responsibilities such as care of the child. Internal needs include protection of the self from disruptive degrees of anxiety and despair. Successful coping by his definition would include the development of defenses sufficient to permit the effective handling of external demands. In unsuccessful coping internal defense becomes so consuming that it hinders the completion of routine tasks.

Matthew's initial condition was unexpected, life-threatening, and of undetermined cause. The neonatologists explained to the parents the severity and probable poor outcome. Both parents clearly insisted "We want everything done." The appearance of their second child was grotesque; grossly puffy and overweight for age, especially in contrast to the tiny premature infants in most of the other incubators. Tubing invaded his arteries, veins, trachea, chest and abdominal walls.

The christening was done immediately. "I don't know how we made it," said his mother later; "I was a basket case." She trained her substitute for work by telephone while recovering from the cesarean delivery, "It was actually a welcome escape!" After discharge she was usually in the NICU six hours a day. Father came daily for two weeks, then every night "except for one,",he noted. On weekends other family members were allowed to visit. All three adolescent step-brothers scrubbed and put on masks to see Matthew for the first time. "They were impressed and frightened (he was on a ventilator then); the second time he looked more normal without so many tubes and breathing on his own." The two year-old sibling reacted differently; "He didn't act afraid. Maybe he thought all babies come like that. He kept saying 'my baby!' and looked happy."

Matthew's mother: "The only thing I really would have liked to do is lie in the sun and not think."

The NICU is an extremely complex and busy area. The parents dealt with numerous physicians and a group of nurses who remained close to the family, even after discharge. "Our biggest fear during the first few days was whether he would make it." To everyone's surprise almost all of Matthew's many kinds of damage improved except for his kidneys, feeding problems and potential brain damage. The challenges then changed to the slow preparation for home and the beginning of other fears. "But I wanted him home, and I knew I could take care of him there," said his mother.

This was not an unfounded statement. His mother participated in his care daily, quickly mastering the nursing tasks. She learned peritoneal dialysis together with the first nurses trained to perform it for Matthew. His father was less involved in these tasks. After six weeks, Matthew was ready for discharge. His remaining active problems were "only" peritoneal dialysis and feeding difficulties. It is difficult to surmise Matthew's own experience in the NICU. His mother said, "Matthew would always cry when we were undressing him at home. I'm sure he remembers the NICU and the pain."

Matthew's mother's coping during this period was manifested in learning to successfully manage the external need; the techniques for giving his care at home.

Coping at home

Matthew's room was complete with crib, mobile, equipment for tube feeding and dialysis as well as a blood pressure cuff and stethoscope. Since the only tube permanently in his body was the dialysis catheter in his abdomen, there was no need for intravenous equipment. Over time, nutrition became a nagging issue as Matthew had difficulty sucking his formula; he frequently spit it back up and appeared to dislike the whole affair. "It was like force-feeding him." Mother attempted to bottle-feed every few hours, day and night. "I didn't want him to have to depend on tube feedings again—but it didn't work out. I was exhausted and he didn't gain weight." It became necessary to insert a tube into his stomach for each feed and use a food pump to provide continuous night tube feedings. Formulas were created for him and modified frequently in accordance with his needs. "It felt like playing the role of a mad scientist every time we mixed up his formula; so much of each aminoacid!," his father expressed. After several weeks his weight gain became more consistent.

Dialysis by peritoneal exchange allowed Matthew to be home for treatment instead of making frequent visits to a hemodialysis center. Despite this independence, tremendous amounts of dedication were required from the parents. The dialysis exchange was done, principally by mother, every 4 hours around the clock.

The first interview

Mother: During the first interview his mother appeared very intense, seeming oblivious to the videocamera and the approaches of Timmy, the older child. She described herself as more actively involved in Matthew's caretaking than his father from the beginning. However, she also felt somewhat overwhelmed by taking on almost all of his care as well as the housekeeping and care of her other child. "I really wanted someone to knock on my door and take over, without me needing to ask them," she said.

Help in general tasks had been offered by her siblings, friends and church members; yet, at the time of the first interview, she had refused it. In addition, the specific tasks of tube feeding and dialysis could have been performed by a respite nurse. Matthew's mother could not clearly explain why she had not, up to then, accepted any help except one afternoon of shopping when her family insisted. Yet she confessed that "the only thing I really would have liked to do is lie in the sun and not think."

A positive emotion she commented on was increased closeness to her husband as a result of the stress of Matthew's illness. Equilibrium could be easily threatened, however. A visit to the hospital "brought back all the tiredness, frustration and fear. And that was just picking up a prescription!"

Father: Matthew's father was not present in the first interview, although he had stated that he wanted to be. In that interview his wife talked about her husband's experiences with Matthew. She mentioned that he wanted to participate more in Matthew's care, but found it difficult. For example, nightly the feeding tube had to be slipped into one of Matthew's nostrils; alternating the nostril each night. "He would try every couple of days and chicken out as soon as Matthew started to squirm. The last time he tried, it was the turn of the most stubborn side. I said—forget it, do the easy one and I'll do the other twice in a row. But he wanted to do it 'right'! Of course, he couldn't get it in that time."

His wife felt that emotions were not easy for him to express. She said "I thought it might be easier if he could talk about what he felt, too. So when we chatted about it he said the only feeling he could get in touch with was . . . anger."

Solnit and Stark (1961) compare the well-known stages of dealing with death to those involved in accepting the birth of a defective child. One basic contrast is the painful, prolonged struggle toward the goal of accepting reality. Unlike a bereaved parent, the parent with a living child with special health care needs faces an enormous load of urgent and absorbing caretaking. The impact of the disease is daily and unrelenting. The task is two-fold; mourning the anticipated healthy child, and accepting the defective one. The shock of an abnormal delivery ending a previously normal pregnancy is another factor which may hinder the first step of an already uphill climb.

These authors describe two extremes of parental coping: The first is guilt, where the parent attempts to "atone" by giving all of their energy to the infant's care, neglecting their family's and their own needs. The second is denial, which often coexists with anger at the institution or staff, and which may result in neglect of the child for fear of facing the intolerable reality. Both extremes are defense mechanisms which are helpful for lessening immediate pain, but not for dealing successfully with the long-term needs of the newborn and his or her family. An early healthy coping response to this kind of loss is to find a balance between guilt and denial.'

Sibling: During the first interview, two-year-old Timmy was extremely active and approached the video-camera menacingly several times. His mother and I were sitting on the couch with four-month-old Matthew lying between us. Timmy attempted to climb onto his mother's lap, but she pushed him away and continued relating the NICU experience. He then headed for the interviewer's lap, but after a few bouncings, was put down.

"Go play downstairs," his mother said, referring to the basement area which was several carpeted steps down, and was where Matthew's medical supplies were kept behind a fence. Timmy played alone awhile and then climbed back up to repeat his unsuccessful attempts to capture his mother's attention. Then he turned back, and the interview was interrupted by several thumps and a wail as he fell down the stairs. His mother made sure he was uninjured and told him to play nearby. Soon afterwards he found a scissors in the kitchen. That was removed by his mother and placed out of his reach.

It appeared that Timmy was not receiving all the attention he needed, especially during the first interview. Interfering factors may have been the interviewer's presence and the effect of normal sibling rivalry for attention. Certainly the caretaking situation appeared to be high-risk; mother seemed to have difficulty supervising the older child at this time.

Coping over time

Rolland (1987) describes phases faced by a family with a chronically ill member. He divides them into crisis, chronic and terminal (if fatal disease). This family could be seen as going through the crisis stage from Matthew's birth, NICU, up to several months after discharge. The chronic stage involves the "day to day living with chronic illness . . . the semblance of normal life . . . a limbo." He stresses the importance of the critical transitional periods, when upheaval may occur as "families reevaluate the appropriateness of their previous life structure in the face of new illness-related developmental demands."

During the second interview, which took place five months after the first when Matthew was nine months old, one comment both parents agreed on was, "I guess the biggest difference is that before we felt more like his doctors and nurses, and now we feel more like his parents."

Matthew's parents, second interview: "Before we felt more like his doctors and nurses, and now we feel more like his parents."

Mother: During the second interview, mother appeared more relaxed and shared tasks with her husband, such as feeding, changing diapers and holding Timmy. She had returned to her job part-time and had a babysitter for both Matthew and Timmy, three times a week. Since Matthew now sucked well, he only needed tube feedings during the night. Also, his dialysis had been changed to a system that worked automatically all night, so that the exchanges every four hours around the clock were no longer necessary.

The respite care nurse had been used, but in moderation; "only eight weeks are covered by insurance—we used respite hours during the evenings, mostly, I think we two need time alone together; if our relationship isn't good, then why bother?," said Matthew's mother, smiling at her husband.

Several days after this interview, however, it seems that the parents had a significant confrontation, and during a visit to the home the nurse found that they were not speaking to each other. After a few weeks the situation seemed to have stabilized again.

Father: During the second interview Matthew's father was fairly quiet. He held, fed, and played with Matthew while mother spoke. When I asked which of them did the 5 a.m. tasks, they looked at each other and laughed. "You always seem to sleep through that, hmmm?," he told her as she hugged him. Then he volunteered, "He's always in a real good mood early in the morning. I turn on the mobile and he'll just watch it and smile, make noises. When I get home from work now I can play with him; it's very different than in the beginning."

Sibling: During the second interview each parent initially held one child, but when Timmy became very distracting, his teenage half-brother was called in the room to watch over him. Later, while sitting with the parents again, Timmy whooped an Indian-call that Matthew was fascinated by and then imitated, to Timmy's delight. The parents also proudly described how Timmy would put on a mask and help with Matthew's sterile dialysis bag changes. "He's very careful and he really helps!" his parents agreed.

Effects of having a chronically ill sibling have been well studied. Breslau, Weitzman, and Messenger (1981) noted no overall statistically significant behavioral changes, although specific decrease in the area of mentation and increase in fighting behavior were noted. The future implications of these findings could not be predicted.

Matthew's father: "I think the future issues will come up when he becomes aware that he's different—I wonder what that will be like for him."

Taylor (1980) interviewed well siblings and found both positive and negative effects. The latter included isolation, feelings of inferiority and guilt associated with anger toward their ill sibling. Among the former were empathy and fruitful experiences in cooperative efforts. As a whole, however, the negative outweighed the positive effects. The effects on Timmy, as he grows up in a family with a child with chronic illness, will remain to be seen.

Matthew: Matthew was rebaptized with participation of church members. His development was found to be only three weeks delayed for age. During the second interview he babbled, grasped and attempted to lift the camera's tripod, and sat up alone. He supported himself poorly when he stood up, but smiled frequently and made good eye contact.

Relatively speaking

Matthew's mother and father emphasized during the second interview; "It's much better now . . . like a normal life, relatively speaking." One of their current "normal" tasks is to receive dialysis supplies every two weeks. Since these are dropped off at their home, sometimes they simply leave a note on their door, saying "Leave everything inside. It's unlocked." When winter driving conditions became a problem for delivery vans, Matthew's father constructed a shed near the mailbox, exclusively for receiving the supplies. Frequently the wrong supplies are sent, all via Federal Express. It is the family's responsibility to return these to the medical supply company themselves for exchange.

Other tasks that involve driving to town are shared by both spouses and include obtaining feeding equipment and formula components, taking Matthew in for laboratory tests, tube changes, check-ups by both primary care physicians and nephrologists and sick calls. The visiting nurse still comes once a week to their home.

Coping in the future

"My greatest concern for his future is the kidney transplant," his mother said. "At first we were told that he'd be on the list at six months of age. When he was getting there I asked if we should make the appointments for HLA typing, and they said—it's different now. He has to weigh twenty pounds first. And I said 'I'm fed up! This is it! What will they tell me next—fifty pounds and five years old?' But that's where we are right now—at twenty pounds he will go on the waiting list, hopefully . . . My wish would be that at next year's interview, he'd have had the transplant. But realistically, I doubt it."

Matthew's father had a different point of view; "Right now I don't think transplant's the biggest issue—things are going all right now, for him and all of us. I think the future issues will come up when he becomes aware that he's different—I wonder what that will be like for him. Also when he starts pulling at his tube—that will be . . . interesting."

Conclusion

During the course of my contact with this family, I encountered changes in both the source of their fears and in their own ways of coping with it. I would agree with J. Lewis, Beavers, Gossett, and Phillips (1976) who conclude "that competence must be considered as a tapestry: reflecting differences in degrees along many dimensions." I am looking forward to next year's interview with Matthew and his family.

References

Breslau, N., Weitzman, M., & Messenger, K. (1981). Psychological functioning of siblings of disabled children. *Pediatrics*, 67 (3):

Chodoff, P., Friedman, S.B., Hamburg, D.A. (1964). Stress, defenses and coping behavior: observations in parents of children with malignant disease. *American Journal of Psychiatry*. 120:743-749.

Lewis, J.R., Beavers, W.R., Gossett, J.T., Phillips, V.A. (1976). *No Single Threat Psychological Health in Family Systems*. New York: Brunner/Mazel.

Rolland, J.S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process*. 26:203-221.

Solnit, A.J., & Stark, M.H. (1961). Mourning and the birth of a defective child. *Psychoanalytic Study of the Child*. Vol. 16 New York: International Universities Press. pp. 523-537.

Taylor, S.C. (1980). The effect of chronic childhood illnesses upon well siblings. *Maternal-Child Nursing Journal*. 109-116.

The Struggle for Control between Families and Health Care Providers When a Child Has Complex Health Care Needs

by
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FLORENCE SHARP

In two studies that I recently conducted, families of children with complex health care needs described a struggle with health care providers for control over their child's care. The families felt that this struggle was the second most stressful component of their entire experience of having a child with special health care needs. Only the uncertainty surrounding the child's survival itself was considered more difficult by the families.

Since 10 to 20 percent of all American children have or will experience special health care needs (Starfield, 1985) and it is estimated that 17,000 children in this country are "medically fragile" or "technology dependent" (U.S. Congress, Office of Technology Assessment, 1987), it is important to understand the basis for such a struggle over control. It is also essential to find ways to prevent or reduce this stress for families (and professionals) who are already coping with psychological, social and emotional disruption, as well as with the sometimes overwhelming financial and daily care requirements that accompany special health care needs and chronic conditions.

The studies

Our first study of families' perceptions of the impact of their child's health condition on the family was conducted in a large northwestern city in which one tertiary pediatric facility provided care for all the children with complex health care concerns. The second study was conducted with participants from several southeastern states who had experienced a variety of health care systems. In both studies a multitrait-multimethod approach, which uses two different methods to measure two or more distinct traits or areas of interest, was employed so that the investigator could look at divergence or covergence of data gathered by distinct methods about the same trait. The primary research method involved qualitative interviews of the families; a secondary method was use of standardized measures. An ethnographic interview allowed study participants, rather than the investigator, to define data appropriate for the study.

The northwest study was conducted over several months, with up to 10 hours of interviews scheduled in each family's home at the family's convenience. Data for the southeast study were collected during an intensive week-long learning retreat, where the researcher and families shared lodgings in an informal camp setting. Methods for the southeast study included one 2- to 3-hour interview for each family, and participant observation. The many informal discussions with families that occurred during the week were written up as field notes and became part of the data set.

Both studies were small, with seven families in the northwest study and ten families in the southeastern study. Since participating families were not selected according to etiology of the child's condition or by family characteristics, family circumstances and the health conditions of the children varied considerably within the samples. We believed that the experience of having a child with complex health care concerns would prove a significant enough commonality to make this study of a very diverse group of families meaningful.

Family adaptation

Each family in both studies reported that they had adapted successfully to the sustained, stressful experiences associated with their child's condition and prolonged interaction with the health care system. All of the children, with the exception of one who had died in the hospital, were progressing well in their family homes. In fact, the children's development far exceeded that expected by involved health care providers.

As the families talked, they seemed to describe a remarkably uniform adaptation to life with a child with complex health care needs. At first, families were overwhelmed and dependent on others for the care of the child and for their own emotional support. Family members were willing to be told what to do and more importantly, what behavior to avoid. Slowly the families began to learn about the health care system and to evaluate the care provided to their child. They came to understand that their child was not going to recover immediately, if at all, and they began to gather information for themselves and to gain skills and knowledge related to the child's care.

The process of adaptation described by families in the two studies was strikingly similar to published reports of stages of behavior and cognition among families in response to childhood chronic health conditions: (Burton, 1975; Waechter, 1977; Thomas, 1978; Rothstein, 1980; 'Sherman, 1980; Koop, 1982; Wartenberg, 1982; Richter-Juarez, 1983; Kornblum and Anderson, 1982; Bristor, 1984). Summarizing the literature, Fortier and Wanlass (1984) reported that families demonstrate consistent responses to their children's diagnoses. They characterized stages of: 1) **impact**, in which parents report feelings of numbness or shock and experience disorganization and anxiety; 2) **denial**, evidenced by disbelief and inability to hear painful information as well as "shopping for cures"; 3) **grief**, a stage of anger, sadness, guilt and helplessness as the reality of the child's condition is recognized; 4) **focusing outward**, a time of energy renewal when family members seek information and options for the child's future; and 5) **closure**, in which a sense of resolution and family solidarity emerge.

The experience of our study families did differ in one important respect from those reported by other researchers: none of the families reported any sense of "closure." Family solidarity did emerge, but not the sense of resolution suggested in other reports.

The struggle for control

Ironically, a struggle between families and health care providers for control seemed to emerge as families reached "healthy" states of adaptation to the realities of their child's complex and ongoing health circumstances, a state which health care providers actively seek to foster in families. As families became knowledgeable about their child's specific needs and idiosyncratic responses to treatment, most of them wished to contribute this expertise to the decisionmaking process of the health care team. Moreover, as families became more informed about their child's health condition and aware of the errors that are inevitable in health care, they came to believe that their own intervention was essential to save their child's life and/or to prevent unnecessary harm or discomfort for their child.

Accustomed to positions of authority and control, health care providers often resist the change in the family's role from that of grateful recipient of services to partner in the health care process. Family passivity may, in fact, be comfortable for both families and providers in situations of acute illness. Families feel less of a need to control a situation that is seen as only temporary and may experience a degree of comfort in submitting to the health care providers' judgment. Health care providers, in turn, may foster passivity by taking on a strong advocacy role, to the point of both defining and meeting the patient's needs.

Such a division of roles is unlikely to work when a child has a chronic condition and families interact with the health care system over a long period of time. Families of patients with chronic conditions desire control over their environment and their lives. They gain experience in negotiating the health care system and, moreover, see no end to their need to negotiate with this system. They also have opportunities to

The Nurse as Scientist

Nursing, like many applied disciplines, is a collection of clinicians, educators and investigators. In the last decade or two nurses have been studying Nursing Science on the doctoral level and graduating a cadre of professionals capable of adding to the body of knowledge in health care.

Nursing research is more than simply a research project conducted by a nurse; it also reflects the area of concern that nurses believe is nursing. It is perhaps easier to anticipate the content of this knowledge base if the focus of the discipline is known. Nursing has been defined by the American Nurses' Association as the ". . . diagnosis and treatment of human responses to actual or potential health problems" (American Nurses' Association 1980, pg. 9). The key, in my view, to understanding nursing is the term "human responses." Nursing cares for and studies people as they respond physically, emotionally, psychologically and socially to "actual or potential health problems." You will find nurses investigating individual physical or physiological responses to cardiac conditions as well as studying families' emotional reaction to a child's death, injury or potential health care concern. The studies described in the accompanying article focused on families' response to a health care concern, that of a child with a complex condition.

Nurses share many interests with colleagues in all health care oriented disciplines. We have a great deal to offer each other. A good place to begin in exploration of the nursing literature is the Index of Nursing Literature in any health science library. Nurses, other professionals and parents now more than ever can benefit from sharing scientific knowledge and from collaborative work in clinical, educational and research endeavors.

American Nurses' Association (1980) *Nursing: A Social Policy Statement*. American Nurses' Association, Kansas City, MO.

observe and to judge the quality of health care providers' work (Rosenthal, Marshal, Macpherson, and French, 1980; Sherman, 1980). Health care providers who work with children with complex health care needs, meanwhile, are contending with their own feelings of helplessness and sadness in the face of the special poignancy of severely or chronically ill young children. They may see families as "troublesome," "interfering," or "dysfunctional" and may resent what seems to be families' lack of confidence in the health care system. If the relationship between families and health care providers—each with their own perspective—develops into a struggle for control, families and professionals can become competitors rather than partners in the care of the child. If competition continues, control even over aspects of the family's life unrelated to the child's care—such as discipline of siblings or use of space in the home—may become foci for the struggle. For families in our two studies, the struggle for control was a major concern, was the aspect of the health care provider/family interaction that engendered the most anger; and, indeed, represented the most burdensome consequence of the child's condition.

The meaning of control

To understand control struggles between health care providers and families of children with special health care needs, it is important to emphasize that control, while having a unique meaning for every individual, is a natural, essential and universal survival strategy. The two related concepts of "territory" and "action territory," described by Bakker and Bakker-Rabdau (1973) are useful in discussing control. "Territory" can be seen as the special area in an individual's life in which he or she exerts control, takes initiatives, has expertise, or accepts responsibility. "Action territory" is further defined as that type of territory in which the individual believes it is his or her prerogative to act, exert control, exercise expertise, and take responsibility for the proper functioning of that realm. (Interestingly, management textbooks encourage individuals seeking to increase their visibility and prestige to increase their action territory. This is done by simply beginning to perform activities for which others are responsible. If the original "owner" of the activity does not protest, the action territory eventually becomes incorporated into that of the "encroacher.")

The concepts of territory and control are inextricably linked with competition between the individual and the environment and between individuals. People will struggle for control over areas they believe to be their rightful territory. Since both families and health care providers have "legitimate" claims to the action territory represented by the care of a child with complex health care needs, a struggle for control is difficult to avoid. Our studies, however, did suggest ways in which this struggle might be reduced.

Respect and support for families

The families in our two studies could describe clearly the approach they wished health care providers to take in their relationships with families. Above all, families wanted respect from providers and support for the family's resumption of the caregiving role for the child. The families wished to be respected for their expertise in their child's condition and care, to be respected as a family unit, and to have their knowledge and suggestions listened to and incorporated into the child's care (Thomas, 1986). They wanted to be considered as members of the health care team, not as objects for discussion and intervention by health care providers.

The approach families prefer is illustrated by the model in Figure 1. As families adapt to their situation, they wish to assume increasing amounts of responsibility for their child's care in the hospital as well as in the home setting. They want health care providers to reduce their interventions with the child and family.

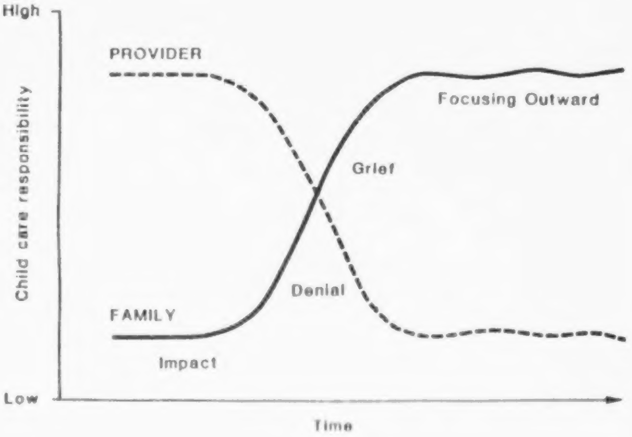

Figure 1
(Thomas, 1986)

The process suggested by this model is not easy. It requires a sophisticated ability to assess the family's adaptation to the child's condition and also a willingness to share with families what has been traditionally the action territory of health care providers. Initial interventions must be designed to support families as they respond to the crisis of their situation and become temporarily dependent on health care providers. As the families move through the stages of adaptation, assuming increasing responsibility for the child's care and seeking more information and autonomy from health care providers, providers must gradually relinquish their position of authority, share their action territory, and encourage family independence. Health care providers must also be aware that the process is not a one-way street: families may required increased assistance periodically as the child's condition worsens or other problems occur to disrupt the family's balance.

This is not an easy process to learn, especially in the context of tertiary care settings, where children with complex health care needs are often first diagnosed and treated. In tertiary care centers, health care providers traditionally are given control and, in addition, are often recent graduates, new to their role. It is very difficult to give up action territory newly acquired. Considerable education and alteration will be needed in a system that currently rewards providers for "doing" rather than for supporting the family to do.

Despite the difficulties involved, reduction of the control struggle with families will more than compensate providers who incorporate this approach into their practice. Health care providers can reduce conflict, empower families, and build the supportive, *collaborative* relationships essential to the care of vulnerable young children.

Bibliography

Bakker, C.B., & Bakker-Rabdau, M., (1973). *No Trespassing! Exploration in Human Territoriality.* San Francisco, Chandler and Sharp.

Bristor, R.W. (1984), The birth of a handicapped child—a wholistic model for grieving. *Family Relations,* 33: 25-32.

Burr, B.H., Guyer, B., Todres, I.D., Abrahams, B., & Choido, T. (1983), Home care for children on respirators. *New England Journal of Medicine,* 309: 1319-1323.

Burton, L. (1975), *The Family Life of Sick Children.* Boston: Routledge & Kegan Paul.

Featherstone, H. (1980), *A Difference in the Family.* New York: Basic Books.

Fortier, L.M., & Wanlass, R.L. (1984), Family crises following the diagnosis of a handicapped child. *Family Relations,* 33: 13-24.

Gruenberg, E.M. (1977), The failures of success. *Millbank Memorial Fund Quarterly,* Winter: 3-24.

Hobbs, N., Perrin, J.M., Ireys, H.T., et al. (1983), *Public policies affecting chronically ill children & their families.*Preliminary report of project: Chronically ill children in America. Nashville, TN: Vanderbilt Inst. for Public Policy Studies.

Ireys, H.T. (1981), Health care for chronically disabled children and their families. In L.B. Schorr (Chair.), *Better health for our children: A national strategy: Vol. 4.* Report of the select panel for promotion of child health. Washington, DC: DHHS (PHS) Pub. #79-55071.

Kettrick, R.G. (1982, Dec. 13-14), *The Pennsylvania program: Case example: The ventilator dependent child.* In: DHHS Pub. No. PHS-83-50194, Report of the Surgeon General's workshop on children with handicaps and their families. Washington, DC: U.S. Government Printing Office.

Koop, C.E. (1982, Dec. 13-14), *Excerpt from keynote address: Case example: The ventilator dependent child.* In: PHHS Pub. No. DHS-83-50194, Report of the Surgeon General's workshop on children with handicaps and their families. Washington, D.C.: U.S. Government Printing Office.

Kornblum, H., & Anderson, B. (1982, Spring), 'Acceptance' reassessed—a point of view. *Child-Psychiatry-Hum-Dev.,* 12 (3): 171-178.

Mercer, R.T. (1974), Mothers responses to their infants with defects. *Nursing Research,* 23: 133-137.

Richter-Juarez, C.L. (1983), *The attachment process between mothers and their chronically ill infants hospitalized for an extended period in an intensive care setting.* Unpublished masters thesis, University of Washington, Seattle.

Rosenthal, C.J., Marshal, V.W., Macpherson, A.S., & French, S.E. (1980), *Nurses Patients & Families.* New York: Springer.

Rothstein, P. (1980), Psychological stress in families of children in a pediatric intensive care unit. *Pediatric Clinics of North America,* 27: 613-620.

Sherman, M. (1980), Psychiatry in the neonatal intensive care unit. *Clinics in Perinatology,* 7: 33-46.

Starfield, B. (1985), The state of research on chronically ill children. In: N. Hobbs & J.M. Perrin (Eds.), *Issues in the Care of Children with Chronic Illness.* San Francisco: Jossey-Bass.

Thomas, D. (1978), *The Social Psychology of Childhood Disability.* London: Methuen & Co.

Thomas, R.B. (1986), *Ventilator dependency consequences for child and family.* Doctoral dissertation, University of Washington, Seattle.

U.S. Congress, Office of Technology Assessment, (1987, May) *Technology-dependent children: hospital v. home care—A technical memorandum,* OTA-TM-H-38 Washington, D.C.: U.S. Government Printing Office.

Waechter, E. (1977), Bonding problems of infants with congenital anomalies. *Nursing Forum,* 16: 299-318.

Wartenberg, B. (1982, Dec. 13-14) *The Pennsylvania Program: Case example: The ventilator dependent child: The child at home.* In: DHHS Publication No. PHS-83-50194, Report of the Surgeon General's workshop on children with handicaps and their families. Washington, DC: US Government Printing Office.

Call for Papers

The first International Conference on Family Support, which will take place in Stockholm, Sweden, August 14-18, 1988, invites abstracts for oral and poster presentations on topics including professional/family collaboration, the impact of disability on family members, community service models, intervention programs, cultural and ethnic aspects of family support and research with families, among others. **The deadline for receipt of abstracts is March 31, 1988.** For more information contact The Institute for Integration, Norrmalmstorg 1, S-111 46 Stockholm, Sweden, tel: t46-8-11 20 06.

The Third Biennial Meeting of the International Association for Infant Mental Health, which will be held September 22-25, 1988 in Providence, Rhode Island, invites proposals for papers, posters, symposia, workshops, conversation hours and exhibits on theoretical, empirical, clinical, policy or training issues related to the early detection of at risk infants and families and prevention/intervention with at risk infants and families. **The deadline for receipt of submissions is March 31, 1988.** For information contact Janice Miller, Brown University Program in Medicine, Office of Continuing Medical Education, Box "G", Providence, RI 02912, tel: (401) 863-3337.

The **American Journal of Mental Retardation (AJMR)** will devote a special issue to family assessment and research, with a focus on innovation in measures (with evidence of psychometric reliability and validity) and design strategies, as well as advances in conceptualization and empirical findings. **The deadline for submission is May 1, 1988.** For information about AJMR editorial policy and peer review, write to guest editors Rune Simeonsson, Marty Wyngaarden Krauss or Sharon Landesman at Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, CB #8180, Chapel Hill, NC 27599.

Training Parents For Home Care of Babies Who Have Bronchopulmonary Dysplasia: The Role of the Parenting Specialist

by
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and
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and
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Thomas Jefferson University Hospital

Recently, a parenting specialist (see side bar) worked with health care staff to increase the effectiveness of a program to train parents to care for babies with bronchopulmonary dysplasia (BPD) in their own homes. This included reviewing all training activities as well as developing specialized training materials for use with parents. The following is a description of this interdisciplinary effort.

BPD: The effect on infants, their parents and health care staff

BPD is a chronic lung disease of newborn infants. It is believed to be caused by oxygen administered via a ventilator for the treatment of respiratory distress in premature infants. In the United States, BPD is reported to occur in 15-38% of the infants who are born each year weighing under 1500 grams and who require mechanical ventilation.

Many infants with BPD are associated with difficult, complicated and prolonged hospital courses. During this time these infants are exposed to numerous noxious stimuli; endotracheal intubation; suctioning; insertion of NG tubes; heel pricks; IV insertion; and restraint. These procedures, combined with the constant bombardment of monitor and ventilator alarms and bright lights, appear to overload the infants' innate coping mechanisms. The infants are not able to recognize experiences and often display heightened episodes of irritability and agitation. Hospital staff have observed that these infants frequently posture, arch their bodies and thrust their arms and legs. It requires patience and skill for anyone—parent and staff—to care for and comfort these infants.

Thus, the initial fears and anxieties that parents have about nurturing their premature babies are further complicated for parents of babies with BPD. Many parents find it difficult to accept the chronicity of their infant's disease. They become frustrated with the slowness of weaning from the ventilator. They lose patience with staff and with the infant. They want their infant to be healthy. They struggle with the fact that the infant's recovery will be characterized by small gains and frequent setbacks. They realize that caring for their baby at home will require that they perform complicated tasks and manage their baby's care without the immediate support of the health care team.

The Parenting Specialist

Traditionally, professional work with parents focused on areas of dysfunction and was primarily remedial. New insights about the normal needs of parents have, however, sparked a growing emphasis on work with a more developmental focus that is both educational and supportive. While the content of the two approaches often look similar, there are clear differences in the style, the methods used and the relationship that the professional establishes with the parent.

Persons who specialize in parent support and education are emerging from many disciplines: social work, psychology, early childhood development, pediatrics and education. Today these persons, sometimes referred to as "parenting specialists," can be found in hospitals, child care centers, pediatric clinics, private pediatric practices, school systems and community based family support programs.

The primary role of a parenting specialist is to enhance a child's growth and development by working simultaneously in two ways: first, by helping to deepen the insights of the adults in a child's life; and second, by helping to strengthen the partnership between the child's family and the staff related to that child. In order to do this, a parenting specialist will have a broad base of knowledge in several of the following areas: normal child development, parent's developmental process, adult education concepts and strategies, family systems, parent-infant/child attachment, and practical aspects of caring for young children at home as well as in settings outside the home, such as hospitals, out-patient pediatric programs, and child care.

A parenting specialist will have demonstrated skills in a number of areas. For instance, a parenting specialist will be able to enhance or expand positive intuitive skills of parents in relation to their children, and likewise, will be able to enhance or expand positive intuitive skills of staff in relation to parents. A parenting specialist will have the skill to encourage and strengthen an *inter*dependent relationship between parents and staff. A parenting specialist will have the skills of observation and the ability to coordinate and collaborate with people from many different disciplines.

The physicians, nurses, social workers, respiratory and developmental therapists who work with babies who have BPD frequently experience frustration with their efforts to train parents to care for these babies at home. Staff report that many parents fail to keep appointments for training. Other parents visit their baby frequently, but the visits take place over various hospital shifts, with training being done by whatever staff member is available. And often even the parents who have been trained and who are technically ready to assume responsibiliity for the baby's care will press staff to delay and further postpone the date of discharge.

Project description

In response to staff frustration, a parenting specialist was engaged to work with staff at Thomas Jefferson University Hospital and Children's Rehabilitation Hospital in Philadelphia. These institutions are working together on the development of a system of care for babies with BPD that encompasses tertiary, rehabilitative and home care. This comprehensive project is supported in part by a SPRANS grant from the Maternal and Child Health Division of the US Public Health Service. In addition to direct care, this project includes parent education, research, outreach education and staff development.

Evaluation of the parent education program

The parenting specialist identified the questions that were used to guide the evaluation of the existing parent education program. These questions were drawn from the literature on parent support and education as well as from the specialist's clinical experience with parents in a variety of settings. Some of the basic questions were as follows: What did the parents need—as parents and as learners? What assumptions did staff members hold about parents—as parents and as learners? What educational styles were most frequently used with parents? What educational materials were currently being used with parents? Were there any training materials that staff found to be useful in their work with parents?

Each member of the health care team was interviewed individually. The interviews were unstructured. Each staff member was asked to comment on their needs as educators and on their perceptions of the needs of the parents. In-service training sessions, facilitated by the parenting specialist, were offered to all staff. These group sessions provided a forum for staff to discuss their experiences and concerns about working with the parents in the BPD project. They also provided an opportunity for peer reinforcement of positive intuitive behaviors. They also resulted in the identification of individual skills and many creative educational techniques that various staff members employed.

Perhaps most important, members of the health care team taught the parenting specialist each of the procedures that parents are required to learn in order to care for their infants at home. Through this direct participation in the teaching-learning process, the parenting specialist was able to critique directly with individual staff members their educational styles and their assumptions about the educational needs and competencies of parents.

To learn more about the parents' needs, the consultant observed parents caring for their babies at both hospitals. A home visit was also made to a parent who had a baby that had recently been discharged from the rehabilitation hospital.

And finally, the consultant reviewed material developed for parents by national organizations, pharmaceutical companies and equipment companies. Several commercial publications for parents were also included in this review.

Problems with parent education for home care

A review of the parent education activities and materials helped to clarify the problems with the parent education program. Some of the problems related to the way the educational activities were structured and organized; other problems were related to the nature of the task; and, additional problems resulted from insufficient resources.

One problem was that skills were taught to parents in a random fashion. The professional staff's routines often determined the sequence of teaching rather than the readiness or educational needs of the parents. Another problem was that there was considerable variation in the medical care techniques staff used. This caused confusion for parents who may have been taught three or more different ways to perform the same procedure. Similarly, different staff emphasized different aspects of a condition or procedure, adding further to parents' confusion and insecurity.

Because of their experience and training, staff thought of the required home care procedures as simple, familiar, uncomplicated parts of their daily routine. It was often difficult for some professional staff to remember that, to many of the parents, the procedures were foreign, complicated and overwhelming tasks.

Staff felt responsible for ensuring that the medical care the infant received at home was of the same quality as the care provided in the hospital. This unrealistic standard, plus the emphasis on expediting the move to home, tended to increase the pressure staff felt to have parents assume responsibility for care of their infant. Parents felt this pressure and responded by withdrawing or becoming even more anxious. The infrequent or irregular visiting that is so frustrating for staff is often a strategy parents employ to avoid the pressure to do too much, too soon.

Most staff had good intuitive skills for routine parent education. Few, however, had the experience or training required for such an extensive and complicated educational task. The parents of the babies in the BPD project had a wide range of reading levels and intellectual abilities. Each had experienced a serious disruption to his or her own process of development as a parent. They were often scared, angry, fearful and resistant to the idea of functioning as doctor, nurse and respiratory therapist. Considerable interpersonal and educational skills were required for staff to engage the parents and keep them focused on a learning activity.

There were few printed materials that were specifically written for staff to use in teaching parents to care for infants with chronic illnesses. None gave specific, step by step descriptions of procedures. A few commercial publications had good basic information about infants, with clear, helpful illustrations of major systems. All of the commercial publications, however, required a reading level that was beyond many of the parents in the BPD project.

Description of the educational materials for parents

The review of the parent education program confirmed the need for specialized training materials. After considering the problems, the needs of the staff and the emotional and educational needs of the parents, project staff began work on the development of training materials for staff to use with parents. The result of this collaboration is *Home Care of Babies with BPD: A Workbook for Parents.*

Although written for parents, the *Workbook* was designed to be used as a teaching tool by professional staff. The *Workbook* format requires notes and comments to be made by parents *and* staff, reinforcing the interdependent nature of their relationship. The *Workbook*'s various educational techniques, vocabulary and division of materials remind and instruct professional staff about how to work effectively with parents. It provides ideas for professional staff about how to manage the complex task of strengthening a parent's self-confidence while engaging the parent in the learning process.

Material for the *Workbook* is divided into teaching modules. Each module includes a single topic or skill and most can be covered during one hospital visit. For example, the section on naso-gastric feeding has a module to define and illustrate naso-gastric feeding, a module that details how a parent feeds a baby with a naso-gastric tube and, a module on how to change a naso-gastric tube.

Each module is designed to build on the information and skills covered by the previous module. For example, a single module is designed to address parents' fears about oxygen. This module is to be completed before parents begin any training in the use of oxygen systems. This learning progression helps parents deal first with their feelings, next with simple concepts and finally with more sophisticated treatments.

The *Workbook* is not bound. It consists of individual pages to be placed in a ring binder. Parents are given the pages they need as they work on the various procedures. This allows for each workbook to be individually tailored to the child's care plan and the parent's needs.

Each of the major learning styles—visual, kinesthetic and auditory—is addressed in the workbook. This is accomplished by including clear, simple illustrations; a

HOME CARE OF BABIES WITH BPD: A WORKBOOK FOR PARENTS

Purpose

To be used by physicians, nurses and allied health personnel in training parents for home care of babies with Bronchopulmonary Dysplasia.

Features

Provides a standard, base level of information.

Designed to allow additional information or emphasis to be provided in response to a parent's needs and the unique needs of his/her baby.

Provides a model for a teaching style and vocabulary that is effective in work with parents who have no medical training.

Addresses the variety of learning modalities that will be represented in the lay population—visual, auditory and kinesthetic (eg. clear, simple drawings; coloring tasks; equipment manipulation tasks; etc.).

Each section is self-contained so that parents are only given the sections they need for their baby.

The *Workbook* can be used in the BPD unit of any hospital.

The *Workbook* is convenient to store. It is color coded by section for ease of use.

Table of Contents

A. What Is Normal for Your Baby?
B. Day by Day with Your Baby
C. Your Baby's Respiratory System
D. Gastro-Esophageal Reflux
E. Gavage Feeding: What Is It?
   Gavage Feeding: How to Do It
   Gavage Feeding: Changing the Naso-Gastric Tube
F. Gastrostomy Feeding
G. Keeping Your Baby's Airway Clear: Humidifiers
   Keeping Your Baby's Airway Clear: Nebulizers
   Keeping Your Baby's Airway Clear: Aerosol Therapy
H. Questions and Answers About Using Oxygen in Your Home
I. Your Baby's Oxygen System
J. Tracheostomy Care: Questions and Answers
   Tracheostomy Care: Skin Care
   Tracheostomy Care: Changing the Strings
   Tracheostomy Care: Changing the Tracheostomy Tube
   Tracheostomy Care: Emergency Procedures
K. Your Baby's Medications
L. Making Sense Out Of Medical Terms

For further inquiries or to order copies of the Workbook at $6 each:

Nancy Johns PhD (215-438-7234) or
Cathie Harvey MSW (215-567-2562)
Philadelphia Parenting Associates
229 W. Upsal Street
Philadelphia PA 19119

diagram of the respiratory system to be colored; equipment manipulation tasks; and charts for parents to record the infant's medications, equipment requirements and progress.

The vocabulary, writing style and tone allow parents to participate in the training with maximum opportunities for success. Parents are responsible for reporting on the skills they have mastered; and identifying specific areas where they needed additional practice or assistance. Important instructions that occur frequently, such as hand washing and holding the baby during feedings, are emphasized with symbols.

Warnings or special instructions are presented with full explanations. Manuals for health care staff commonly include caveats such as, "*Never* allow water to enter the trach tube." Many parents, however, are frightened and immobilized by this kind of direction. They probably do not have a level of proficiency that allows them to function without some degree of error. They may not know the full implications of failing to observe the caveat. Thus, for a parent, it is more important to understand why it is a problem for water to get into the tube; to learn skills for avoiding the situation; and to have clear directions about what to do if it happens.

The *Workbook* provides anticipatory guidance for dealing with advice from family, friends and neighbors. These traditional "authorities" on child care may not understand the special needs of the baby with BPD and often will try to undermine the care plan. Evaluating and responding to this well-intentioned advice requires that parents have a clear understanding of the rationale for the care plan and, when possible, to have practiced some replies for use in these situations.

Only basic information is provided in the *Workbook*. Health care staff use the *Workbook* in conjunction with a manual that details the complete teaching protocol.

Field test results

By the time the *Workbook* was printed and available, funding for the continued involvement of the parenting specialist had ended. However, the parenting specialist arranged for the *Workbook* to be field tested by staff in a BPD program at another tertiary care facility. The field test showed that the *Workbook* helped to keep the training sessions focused, logical and complete—despite the many distractions that occur during the course of a bedside or a clinic session. The parenting specialist observed that the *Workbook* supported and enhanced the teaching of staff members who had good educational skills. With less skilled staff, use of the *Workbook* helped to order the way in which information was presented, to make the vocabulary more appropriate and to ensure that basic information was covered. While the material facilitated an increase in the amount of interaction between parent and staff member, it was less than expected for the experienced staff members and inadequate for the less skilled staff members. It did however, change the pattern of staff reciting information to parents. Instead, staff members began with questions about what parents already understood or had heard about a procedure and then made a decision about how to proceed with the training.

There has not been an opportunity to evaluate parents' responses to the *Workbook*. Informal comments from parents indicate that they appreciate having the personalized information to refer to and to share with pharmacists, general practitioners, and family members. With even the modest changes that occurred in the pattern of the parent-staff interaction, parents' participation in the training increased. Parents asked more questions, made more requests for clarification and offered more substantive comments.

Summary

Each year, health care professionals will be required to train increasing numbers of parents to care for their chronically ill infants at home. This training is more complex than traditional patient education, and it raises many questions and presents new challenges. A parenting specialist can assist health care staff with this training in two ways: first, in the determination of what materials and methods are most effective in training parents for home care; and second, in identifying the kind of training and support that health care staff will need to be able to design and implement effective parent education programs.

New Training Opportunities

The **Hunter College School of Social Work** and the **Infant and Parent Development Program** at the **Graduate School of Bank Street College** will offer students an opportunity to obtain MSW and MS degrees through an 80-credit educational program. In addition to a required curriculum of courses offered by both schools, each degree includes a year of supervised internship; with faculty approval, this may be arranged at a student's work site. Hunter College and Bank Street College are both located in New York City. For further information contact Dr. Nancy Balaban, Bank Street College of Education, 610 West 112th Street, New York, NY 10025, tel: (212) 663-7200, x410 or Dr. Martha Haffey, Hunter College School of Social Work, 129 East 79th Street, New York, NY 10021.

The **University of Washington** has received a 3-year personnel preparation grant from the U.S. Department of Education to prepare early childhood special educators for work with children from birth to two years of age with special needs and with their families. Practicum placements are available in a regional referral and diagnostic center and in an infant program with a transdisciplinary training approach. For information, contact Dr. Rebecca Fewell, Experimental Education Unit WJ-10, University of Washington, Seattle, WA 98195, tel: (206) 543-4011.

National Center Notes:

By Eleanor S. Szanton

Many of our readers were not able to come to the highly successful celebration of NCCIP's tenth anniversary and training institute and therefore were not able to hear the recognition given by our president, Dr. Sally Provence, to five individuals whose contributions to our nation's infants and families and to the development of NCCIP have been extraordinary:

Irving Harris and **Bernard Levy**—recipients of the first **Selma Fraiberg-Leon Yarrow** Distinguished Service Award

Reginald Lourie—recipient of the 1987 Dolley Madison Award

Those who did come may wish to read again these moving tributes.

Presentation of the 1987 Selma Fraiberg-Leon Yarrow Distinguished Service Awards to Irving Harris and Bernard Levy

Sally Provence, President
National Center for Clinical Infant Programs

The National Center for Clinical Infant Programs has created The **Selma Fraiberg-Leon Yarrow** Distinguished Service Award to recognize individuals who are outstanding in their service to children and parents. We thought it fitting to name this award for two of our founding members, both of whom died at the height of their productivity and creative work.

All of you will have seen in your program books the brief descriptions of some of the accomplishments of **Selma Fraiberg** and **Leon Yarrow.** It is my privilege to add a few, more personal words about each of them.

Selma's clinical and theoretical sophistication in her field was accompanied by an unusual gift for expressing complex ideas about children in clear and beautiful prose. She was a superb teacher of those who were her students and colleagues and of thousands whom she never met. Her book *The Magic Years* remains one of the books I most admire. I told Selma many years ago—of all the volumes about children that I know, *The Magic Years* is the one I would most like to have written.

Leon Yarrow - Lee - was a man whose quietness and modest demeanor could not conceal the brilliance of his research in child development, his wisdom and the strength of his commitment to the welfare of children. In my reprint file for many years I have had a section labeled simply "Leon Yarrow"—because regardless of the topic, I knew that I wanted Lee's writings close at hand, and as I read reports of new research, I often thought, "I wonder what Lee thinks about this." I always felt enriched by the discussions I had with him.

The contributions of Lee and Selma remain very much a part of the National Center's mission. They live on in our minds and hearts and in hundreds of child development scholars and students.

And now I want to present the first two awards to **Mr. Bernard Levy** and **Mr. Irving Harris.** As your program book shows, each man has made outstanding contributions to children and families, one part of which is their active participation in the work of The National Center.

Irving and Bernie, we recognize your distinguished services to children in your own communities and far beyond them.

Bernie, on numerous occasions you have said to us, when as a very young organization we were struggling with questions about how we might carry out our mission, that if we had a good product, it would do well in the market place. Your loyalty and trust, your insistence that we be clear about what we are doing, your commitment to children and families, continue to inspire and encourage all of us at NCCIP.

Irving, you never cease to amaze us with your know-how and energy, your interest in new ideas, your creative formation of effective coalitions on behalf of children and families. Your belief that there can be a better world and that we must all work toward it has a sustaining power for many of us—perhaps more than you fully realize. We share with you the conviction that if we fail to protect and nurture our young, we shall be guilty of the greatest negligence and folly.

• • • •

Text of the 1987 Dolley Madison Award presented to Reginald S. Lourie:

Leader of modern child psychiatry;

Mentor to a new generation of clinicians and scholars of child health and development;

Compassionate advocate for children and their parents;

Chairman of President Kennedy's Task Force on the Mental Health of Children;

Astute champion of a new clinical discipline concerned with the first three years of life;

and a founder of the National Center for Clinical Infant Programs.

To Reg—who, as a colleague, teacher, and friend, possessed the uncanny ability to see through posturing, indifference and even anger to the core human need for dependency and caring; who always sees in each person the adaptive struggle for closeness and intimacy; and whose legendary anecdotes and stories sculpt truths into view, transforming unsmiling doubters into grinning believers;

and to Reg—who as benevolent mentor, as husband, father and grandfather provides a model for us all.

Infant Day Care Researchers Reach Consensus on Social Policy Issues: Legislators Introduce New Federal Initiatives

As readers of *Zero to Three* are well aware, infant day care researchers differ concerning the effects of out-of-home care for very young children. Concern about the uncertainty created among parents, professionals and policymakers by reports of these differing expert views led the Research Facilitation Committee of the National Center for Clinical Infant Programs, chaired by Kathryn E. Barnard, to convene an "infant day care summit meeting" in October, 1987 in Washington, D.C. Edward F. Zigler led the day-long session, which had two goals: 1) to develop a clear statement on child care for infants that represents a broad consensus of the field; and 2) to formulate, for the benefit of government and private funding sources, an agenda of unresolved research questions and promising approaches to intervention.

> *"When parents have choices about selection and utilization of supplementary care for their infants and toddlers and have access to stable child care arrangements featuring skilled, sensitive and motivated caregivers, there is every reason to believe that both children and families can thrive."*

Researchers attending the NCCIP meeting included J. Lawrence Aber, III, Barnard College of Columbia University; Kathryn E. Barnard, University of Washington; Jay Belsky, Pennsylvania State University; Alison Clarke-Stewart, University of California-Irvine; Byron Egeland, University of Minnesota; Ellen Galinsky, Bank Street College of Education; Stanley Greenspan, George Washington University School of Medicine; Thomas J. Gamble, Edmund L. Thomas Adolescent Center, Erie, Pennsylvania; Carollee Howes, University of California-Los Angeles; Michael Lamb, National Institute for Child Health and Human Development; Deborah Ann Phillips, University of Virginia; Sally Provence, Yale Child Study Center; Marian Radke-Yarrow, National Institute of Mental Health; Henry Ricciuti, Cornell University; Albert J. Solnit, Yale Child Study Center; Theodore D. Wachs, Purdue University; and Edward Zigler, Yale University. T. Berry Brazelton, Harvard University; J. Ronald Lally, Far West Laboratory for Educational Research and Development; and Sandra Scarr, University of Virginia assisted in the development of, and endorsed, the group's statement.

The researchers agreed that when parents have choices about selection and utilization of supplementary care for their infants and toddlers and have access to stable child care arrangements featuring skilled, sensitive and motivated caregivers, there is every reason to believe that both children and families can thrive. Since such choices do not exist for many families in America today, the researchers stressed the urgent need for improved child care options and services for young children and their families.

The 50 percent of American mothers with children under one year of age who are now in the labor force represent a new social phenomenon, and make the issue of infant day care one of concern to the whole nation, researchers agreed. Both mothers and fathers of young children are experiencing significant stress and loss of productivity when high quality care for infants is not available and affordable, and when staying at home to care for an infant is not economically feasible. Inadequate care poses risks to the current well-being and future development of infants, toddlers and their families, on whose productivity the country depends.

Meeting participants emphasized that the quality of infant/toddler care matters enormously, whether it takes place in the home or in a child care setting, and whether the caregivers are a child's parents or another familiar trusted adult. According to the research group, both the home and child care environment should provide an infant or toddler with:

- Physical protection and attention to health and nutrition;
- Awareness of and respect for individual differences in infants and toddlers;
- Sensitivity to the infant's cues and communication;
- A capacity to shift caregiving practices as the infant develops and changes; and
- Warm, loving human relationships based on constancy of care.

Child care, the researchers stated, must be viewed as a support to the whole family. A comfortable "blend" and close collaboration between parents and caregivers are important for the well-being and the development of both children and parents. Since the sensitivity, skills and commitment of the caregiver determine to such a large extent the quality of the child's experience in supplemental care, the researchers pointed out the urgent need to improve salaries, working conditions and training for child care providers, whether in center-based or family day care settings.

Meeting participants also emphasized the need for better understanding of the complex interaction among factors that influence the development of young children and families and of the role of day care in the lives of infants, toddlers and their parents. They suggested, among a variety of research initiatives, that parallel prospective longitudinal studies, in which investigators in different parts of the country could

NANCY P. ALEXANDER

use some common measures in their research, would be likely to yield data useful to child development scholars, policy-makers and parents. Such studies might look at family processes before the decision is made to use supplementary care for an infant, and at indicators of the quality of care, whether parental or supplementary.

Growing attention to the need to improve the country's supply of accessible, affordable high quality child care, including care for infants and toddlers, is reflected in recently introduced federal child care legislation. Senator Christopher Dodd and Representative Dale Kildee have introduced two bills, The Act for Better Child Care Services and the New School Childcare Demonstration Projects Act.

The **Act for Better Child Care Services** (S.1885/H.R. 3660) is comprehensive federal legislation which would authorize $2.5 billion to help states make child care more affordable for low- and moderate-income families; increase the number of child care facilities and the number of qualified staff available to all families; and coordinate child care resources to ensure their efficient use and help make a wide range of child care options available to parents. As of early February, 1988, the Act had 34 co-sponsors in the Senate and 149 in the House of Representatives. The Act for Better Child Care addresses the special needs of infants, toddlers and their families in provisions concerning reimbursement rates, family support services, training for parents and providers, and standards. Approximately 100 national organizations, including the National Center for Clinical Infant Programs, are members of the Alliance for Better Child Care, which developed the proposed legislation. A 15-page booklet, *"Child Care: The Time is Now"* presents key data about child care in the United States (including child care costs in selected cities, state child care standards and the salaries of child care workers); current federal, state and private roles; and a summary of the Act for Better Child Care Services. Single copies of the booklet may be purchased for $1.95 from the Children's Defense Fund, 122 C Street, N.W., Washington, D.C. 20001, tel: (202) 628-8787, with bulk rates available.

The **New School Childcare Demonstration Projects Act** (S.1995/H.R. 3841) would provide financial assistance to states for the establishment of child care demonstration projects within local public school systems. Such projects would feature child care for children ages 3 to 12 in school buildings themselves; monitoring, training and support for networks of local family day care homes that provide care for infants and toddlers; a family support system for parents of infants; and information, referral and other specialized services. Evaluation of the impact of these projects would also be mandated. The rationale for this approach was developed by Edward Zigler and is described in the article by Robert J. Trotter, "Project Day Care," in the December, 1987 issue of *Psychology Today*.

Senator Orrin G. Hatch and Representative Nancy Johnson have introduced **The Child Care Services Improvement Act.** Provisions of this bill include "seed money" to local organizations seeking to address unmet child care needs, including infant care; liability reforms for child care providers; a revolving loan fund to enable family day care providers to meet licensing/accreditation standards; consumer and provider education; encouragement for employers to develop flexible work policies and several child-care related tax benefits, including a tax exemption for parents who choose to stay at home for up to six months with newborns or newly adopted children.

For Your Information

The **Omnibus Budget Reconciliation Act of 1987, P.L. 100-203** provides a number of changes in Medicaid eligibility related to pregnant women and children, beginning July 1, 1988.

- States are permitted to extend Medicaid coverage to pregnant women and to infants up to the age of one in families with incomes up to 185 percent of the federal poverty line. Families with incomes over 150 percent of the poverty line may be charged monthly premiums for coverage.
- States may provide Medical coverage to children up to the age of five whose family incomes are below the federal poverty line.
- States *must* provide Medicaid coverage to all children under the age of seven, born on or after September 3, 1983, whose families meet AFDC income and resource requirements.

The legislation also establishes a 36-member bi-partisan National Commission on Children to make recommendations by September 30, 1988 on the health of children, social and support services for children and their parents, education, income security and tax policy. Funds have been appropriated as well for demonstration projects to provide residential care for infants abandoned in hospitals and for a study of foster care for children with AIDS.

The **Bureau of Maternal and Child Health and Resources Development** has announced in the Federal Register of February 4, 1988 that Fiscal Year 1988 funds are available for grants for the following activities: Special MCH projects of regional and national significance (SPRANS) which contribute to the health of mothers, children, and children with special health care needs; MCH research; training in MCH; genetic disease testing, counseling and information services; and hemophilia diagnostic and treatment centers. Deadlines for receipt of applications differ for the several categories of grants; they range from March 23 to August 1, 1988. Requests for technical or programmatic information should be directed to the Director, OMCH, BMCHRD, HRSA, Room 6-05, Parklawn Building, 5600 Fishers Lane, Rockville, MD 20857. Requests for grant application materials should be made to the Grants Management Officer, Office of Program Support, BMCHRD, Room 11A-18, Parklawn Building, 5600 Fishers Lane, Rockville, MD 20857. Writers should specify the grant category or categories for which an application is requested.

The **Prevention Research Branch of the National Institute of Mental Health** is encouraging grant applications for research that rigorously evaluates preventive interventions aimed at preventing socio-emotional problems in high risk infants and their families (e.g., disorders of attachment) or prevention of early risk behaviors in preschool age children (e.g., poor peer relations). Preventive interventions are implemented prior to or early in the development of mental disorders and precede the need for treatment. They result in the avoidance or interruption of the pathogenic processes leading to dysfunction. Of particular interest are studies focused on high risk, *non*-multi-problem populations, such as children of depressed mothers, or multi-risk populations in which many of the risk factors are malleable. Studies using existing service delivery systems are encouraged, as are studies incorporating a developmental perspective. Follow-up studies of previously successful preventive interventions are of special interest.

For information on application procedures and consultation on developing a grant proposal, contact Victoria S. Levin, Prevention Research Branch, NIMH, 14C-02 Parklawn Bldg., Rockville, MD 20857, tel: (301) 443-4283.

The **Children with AIDS Network,** including educators, medical personnel and allied health and social service professionals, has been formed to pursue three goals: 1) to organize a national forum for ideas, research and information about services for children with AIDS and their families; 2) to support people working with this population, and 3) to inform policymakers about issues and needs concerning families with AIDS. The Network will publish a quarterly newsletter and plans a national conference in Boston in the fall of 1988. For further information, contact Geneva Woodruff, Children with AIDS Network, 77B Warren Street, Brighton, MA 02135, tel: (617) 783-7300.

The **Child Care Employee Project** is administering an 18-month **National Child Care Staffing Study** to examine professional preparation, demographic characteristics, pay and working conditions and rate of turnover among staff of child care centers. Principal investigators of the study are Marcy Whitebook, Executive Director of the Child Care Employee Project; Deborah Phillips, Assistant Professor of Psychology, University of Virginia; and Carollee Howes, Associate Professor, School of Education, University of California at Los Angeles. Data will be collected from forty-five child care centers in each of five cities—Atlanta, Boston, Detroit, Phoenix and Seattle—chosen to represent the diversity of child care delivery systems and regulatory environments found in the United States. Findings of the study, the first comprehensive profile of workers in child care centers in more than a decade, will be disseminated early in 1989. For more information, contact Marcy Whitebook, CCEP, P.O. Box 5603, Berkeley, CA 94705, tel: (415) 653-9889.

With support from the **Bureau of Maternal and Child Health and Resource Development**, the **American Public Health Association (APHA)** and the **American Academy of Pediatrics (AAP)** will develop national performance standards in health, safety, sanitation and nutrition in out-of-home child care programs. "Performance" standards require action on the part of the user to achieve compliance. The APHA/AAP standards, to be completed by June 30, 1990, will be designed to serve as a national reference code for upgrading state and local out-of-home child care codes related to health and safety.

Technical panels will address: environmental quality, prevention and control of infectious diseases, injury prevention and control, health promotion and medical care, nutrition, prevention and management of child abuse, staff health, children with special health care needs, health concerns related to child development and social environment, and the organization and administration of the health component in child care. The project will also conduct a national survey of existing state child care regulations and identify child care programs with exemplary health, safety, sanitation and nutrition practices.

Readers are invited to suggest sources and methods of input, major organizations to whom presentations about the project should be directed, and any ideas which might help make the performance standards more useful. To submit suggestions or request information about the project, contact the Project Director, Debra Hawks at the American Public Health Association, 1015 15th Street, N.W., Washington, D.C. 20005 tel: (202) 789-5600.

Child Care America, a national project of the **Public Television Outreach Alliance,** is a media campaign designed to spotlight the child care issue, especially during "The Week of the Young Child," April 10-16, 1988. A documentary entitled "Who Cares for Children?" will be aired by PBS during prime time on Wednesday, April 13 and episodes of *Mister Rogers' Neighborhood* and *Sesame Street* will address child care themes. Many areas will also be establishing Child Care America Coalitions to sponsor related community activities. For more information, contact Patricia Honisek, Project Coordinator, Child Care America, c/o KCTS, 401 Mercer Street, Seattle, WA 98109, tel: (206) 443-6796.

With support from the **National Institute of Mental Health,** the **Vermont Conference on the Primary Prevention of Psychopathology (VCPPP)** has established a **Primary Prevention Training Clearinghouse** for individuals from a wide range of disciplines interested in providing courses, workshops, or other training opportunities. The Clearinghouse will maintain files of bibliographies, course/workshop outlines and syllabi, media resources, funding and training programs, resource people and other materials pertaining to primary prevention. Primary prevention specialists will be available by telephone to assist in the development of courses or workshops. The Clearinghouse also seeks contributions of reading lists, syllabi and other materials. To receive the Clearinghouse newsletter or to contribute materials, write to VCPPP Prevention Training Clearinghouse, Department of Psychology, University of Vermont, Burlington, VT 05405. Clearinghouse consultants with a particular expertise in infancy are Lynne A. Bond at the University of Vermont, tel: (802) 656-3160 and Betty Tableman, Michigan Department of Mental Health, tel: (517) 373-3627.

Publications

The Responsive Workplace: Employers and a Changing Labor Force—Sheila B. Kamerman and Alfred J. Kahn (New York: Columbia University Press, 1987). $30.00

This book represents the authors' effort to lay the groundwork for "a more realistic assessment of what an appropriate role for employers might be" in meeting the personal and family needs of their employees. Kamerman and Kahn's discussion is informed by data from large and small employers, unions and community studies.

The authors note that flexible benefit plans are "an obvious response" that employers can make to an increasingly diverse work force. Flexible schedules, hours and career paths are discussed. The authors also note that a "basic social infrastructure" of government-provided or mandated minimum health insurance and short-term disability insurance is essential for the entire population. They see a need, too, for a strong governmental role in financing and delivering child care services.

Discussing the special needs of workers with very young children, Kamerman and Kahn note that workers in this situation are neither a large enough constituency nor powerful enough to shape policies at the workplace. For this group, they argue, some protection of time "must be mandated," as with job-protected leaves after childbirth.

State Child Care Fact Book, 1987—Helen Blank, Amy Wilkins and Margaret Crawley (Washington, D.C.: Children's Defense Fund, 1987) Available from the Children's Defense Fund, 122 C Street, N.W., Washington, D.C. 20001 for $5.95.

The findings of the Children's Defense Fund's fifth annual survey on child care funding and priorities in the states reveal that: 1) twenty-eight states spent less for Title XX child care in FY 1987 than in FY 1981, when adjusted for inflation; 2) only 18 states served more children in 1987 than in 1981; and 3) twenty-two states are serving fewer children now than in 1981. Sections of the report address child care standards (only Kansas, Maryland and Massachusetts, for example, require that a caregiver care for no more than three infants; seven states allow a 1:6 ratio); state parental and medical leave legislation; reimbursement rates for center-based and family day care providers; child care administration, licensing officials and advocacy contacts in each state; and state legislative developments in 1987 that either improved or reduced the affordability, availability and quality of child care services.

Unattended Children—Loren Coleman, Susan Partridge and Roy Partridge (Portland, Maine: Human

Services Development Institute, 1987). Available from Research Librarian, Center for Research and Advanced Study, University of Southern Maine, 96 Falmouth Street, Portland, ME 04103 for $9.95.

During 1984-1986, researchers from the University of Southern Maine conducted a three-state study of "lack of supervision" as a form of child neglect. The investigators identified a number of forms of lack of supervision, including outright abandonment, leaving a child in another child's care, leaving a child at home alone, and leaving the child alone in a car or at home but with access to an adult. A fifth—and the most frequent—form was described as "inattentive parenting," in which the adult is near or even with the child but does not supervise at all, so that the child is frequently in danger.

The majority of the sample of cases of lack of supervision consisted of children five years old or younger; 37% were from the birth to three age group. The researcher described mothers of the children as highly vulnerable people whose own developments had been compromised.

The authors found the factor most predictive of overall case improvement to be the quality of the relationship between case worker and family. They also found, however, that even though so many cases involved very young children, a sizable number of workers did not have information about factors (such as the mother's prenatal experience; indications of attachment or of attachment problems; family stress and supports; separation and loss events; and maternal perceptions of the infant) that might have suggested appropriate early or preventive interventions.

What Every Baby Knows—T. Berry Brazelton (Reading, Massachusetts: Addison-Wesley Publishing Company, 1987) $14.95.

Based on the cable television series of the same name, *What Every Baby Knows* follows five actual families through a variety of childrearing situations. Each chapter includes a section on family history; dialogue between Brazelton and the family on issues such as crying, fears or discipline; developmental perspectives on the issues raised; related questions and answers from studio and other audiences of parents; and summaries of follow-up visits with the families. In a sixth chapter, Brazelton describes the family systems theory underlying his work and advocates training in child development for pediatricians, nurse practitioners and family physicians so that these primary care providers "not only can participate in a family's development but also can prevent future illness and behavior problems in the child."

Research on Support for Parents and Infants in the Postnatal Period—C.F. Zachariah Boukydis, editor (Norwood, New Jersey: Ablex Publishing Corporation, 1987) $39.50.

This volume represents an effort to portray the range of contemporary research on social support for early parenting; it addresses the issues of what constitutes social support and how variations in adequate support contribute to developing familial relationships. Chapters on social support in different populations, including adolescent mothers, parents of premature and high-risk infants, mothers of twins, fathers, and single parents, have been contributed by Susan B. Crockenberg; Keith Crnic and Mark Greenberg; Kristin Glaser; C.F. Zachariah Boukydis, Barry Lester and Joel Hoffman; Ross Parke and Barbara Tinsley; and Marsha Weinraub and Barbara Wolf. Chapters that describe efforts to strengthen informal support systems for early parenting emphasize the development of volunteer organizations that provide peer or mutual support resources. Contributors to this section include Lois Wandersman; Deborah Spitz Cherniss; Earladeen Badger and Barbara Goldman; and Carolyn Pape Cowan and Philip A. Cowan.

Reactions to Motherhood: The Role of Post-Natal Care—Jean A. Ball (New York: Cambridge University Press, 1987). $9.95.

The research reported in this volume was undertaken to learn more about the effects that psychological and social factors and the care given by midwives might have upon emotional needs of mothers during the first six weeks of their infants' lives; and to help midwives and other caregivers to make the emotional support of women an integral part of the care they give. The research traced the experiences of 279 British women from the 36th week of pregnancy until six weeks after the birth of the baby, and included the perceptions which mothers and midwives had about each other and about the transition to motherhood.

The author recommends the creation of a supportive environment for new mothers "which is not an optional extra available to some women because of their special needs or because of the particular motivation and skill of individual doctors or midwives, but one which is an integral part of the organizational framework of service." Three elements are seen as key: recognizing the uniqueness of each woman and her approach to mothering; establishing a relationship of mutual trust and respect; and ensuring effective collaboration among providers of care.

Newborns At Risk: Medical Care and Psychoeducational Intervention—Gail L. Ensher and David A. Clark (Rockville, Maryland: Aspen Publishers, 1986). $33.50.

Written by a special educator and a pediatrician, this text is designed for practitioners working with infants and families and for graduate students in early childhood and special education. It focuses on both medical care and educational prevention of disability in infants born at risk; the authors hope to orient professionals to a "new concept of role that diminishes rivalries, heightens the personalization with which service is delivered, and helps to focus attention on the family. . . ."

Various sections of the book discuss high-risk pregnancies and births; identification and assessment of specific disorders and risk conditions; issues and models in early intervention; and aspects of service delivery. One chapter contains excerpts of personal accounts written by eight families who recall experiences before birth, delivery, details of intensive care, memories of caring for high risk infants at home and suggestions for parents and professionals.

Conference Call

March, 1988

March 14-16: *The Johns Hopkins University School of Medicine* (Department of Pediatrics and Division of Child Development) and collaborating organizations will sponsor the tenth annual course on "The Spectrum of Developmental Disabilities: Clinical and Research Issues of Early Intervention" in Baltimore, Maryland. Guest faculty include Pasquale Accardo, Rona Alexander, Robert Cooke, Lilly Dubowitz, Peter Gorski, Robert Haslam, Judy Howard, Heinz Prechtl, Craig Ramey, Isabelle Rapin, Nancy Roizen, Joseph Sparling, Rachel Stark, Bert Touwen, and Renee Wachtel. Write or call Program Coordinator, Office of Continuing Education, Turner 22, 720 Rutland Avenue, Baltimore, MD, 21205, tel: (301) 955-3168. Questions on course content may be addressed to Arnold J. Capute, M.D., M.P.H., tel: (301) 522-5423.

March 17-18: *The Child Care Action Campaign* will sponsor a national policy conference in New York City entitled "Child Care: The Bottom Line." Speakers will include governors Madeline Kunin and Bill Clinton, congresswoman Patricia Schroeder, Gloria Steinem, Phil Donahue and Sheila Kamerman. Write or call Amy Moore, Child Care Action Campaign, 99 Hudson, Suite 1233, New York, NY 10013, tel: (212) 334-9595.

March 27-31: The *American Orthopsychiatric Association* will hold its 65th Annual Meeting, entitled "Adapting to Social Change: Therapy, Technology and Services," in San Francisco, California. NCCIP and ORTHO will sponsor a one-day institute on Monday, March 28 entitled "Working with Infants, Toddlers and Their Families: Issues and Strategies for Identification, Assessment, Treatment, Consultation and Program Evaluation," with faculty including Joanna Erikson, J. Ronald Lally, Jeree Pawl, Emily Schrag and Stephen Seligman. Sessions are also scheduled in "Infant Attachment, Nonmaternal Care and Maternal Employment: Clinical Implications," "Prevention and Treatment: Power Struggle or Partnership? The Role of Family Resource Programs in the Field of Mental Health," "Preventive Interventions with Infants, Young Children and Their Families," "Empowering Parents: Another Approach to Partnerships," and "What Does the Corporate World Say about Meeting Children's Needs?" For information write or call American Orthopsychiatric Association, 19 West 44th Street, Suite 1616, New York, NY 10036, tel: (212) 354-5770.

April, 1988

April 8: *Kennedy Memorial Hospital for Children* and *Boston University School of Medicine* will present a conference on "Servicing Young Children with Special Needs" in Newton, Massachusetts. Jack P. Shonkoff will be the keynote speaker. Contact Mary Lou Fries, Director of In-service Education, Kennedy Memorial Hospital for Children, 30 Warren St., Brighton, MA 02135, tel: (617) 254-3800, ext. 151.

April 10-13: The *Department of Maternal and Child Health in the School of Public Health, University of North Carolina,* will present the 15th annual Regional Conference on Maternal and Child Health, Family Planning, and Services for Children with Special Needs in Chapel Hill, North Carolina. The conference is designed for health professionals in DHHS Region IV. For information, contact Annette Parker, Office of Continuing Education, UNC-CH School of Public Health, CB 8165 - Miller Hall, Chapel Hill, NC 27599-8165, tel: (919) 966-4032.

April 14-15: The *Massachusetts Early Intervention Consortium* and the *University of Massachusetts Medical Center* will sponsor a conference in Marlborough, Massachusetts entitled "Current Perspectives on Child and Family Assessment: A Team Approach." For more information, contact Susan Lane, tel: (617) 856-3041.

April 21-24: *The Sixth Biennial International Conference on Infant Studies* will take place in Washington, D.C. and will include symposia, oral presentations and poster sessions. For information, write to Dr. Nathan Fox, Program Chair, ICIS, University of Maryland, Institute for Child Study, College Park, MD 20742.

April 25-26: The *Michigan Association for Infant Mental Health* will hold its 12th annual meeting in Ann Arbor, Michigan, focusing on "Collaborating on Behalf of Special Needs Infants and Young Children: Challenges for Practitioners, Educators and Social Policy Makers." For more information, write to Thomas Horner, Child and Adolescent Psychiatric Hospital University of Michigan Medical Center, Ann Arbor, MI 48109.

April 27-30: *Children's Hospital National Medical Center, Division of Child Protection* and the *National Center on Child Abuse and Neglect,* DHHS will sponsor a National Symposium on Child Victimization in Anaheim, California. Topics to be addressed include approaches to early developmental assessment and evaluation, cultural dimensions to multi-disciplinary intervention and the crisis in out-of-home care, among others. Write or call Conference Coordinator, Division of Child Protection, CHNMC, 111 Michigan Avenue, N.W., Washington, D.C. 20010, tel: (202) 939-4960.

May, 1988

May 18-21: The *National Association of Perinatal Social Workers* will hold its 12th annual conference in San Antonio, Texas on the theme, "Perinatal Social Work: Creative Practice in a Time of Limited Resources." Contact Carolyn Chen, ACSW, tel: (512) 925-5704.

May 21: The 19th Annual *Margaret S. Mahler Symposium* will be held in Philadelphia on the topic "Current Research in Early Childhood Development." Speakers will be John F. McDevitt, Patricia Nachman and Calvin F. Settlage. For information contact Selma Kramer, M.D., The Medical College of Pennsylvania, Department of Psychiatry, 3200 Henry Avenue, Philadelphia, PA 19129, tel: (215) 842-4145.

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May 22-26: *The University of Nebraska College of Nursing* and *Meyer Children's Rehabilitation Institute* will sponsor a faculty institute in Omaha entitled "Getting Started Together: Health and education communities working with infants at risk, or who have developmental disabilities, and their families." Contact Audrey Nelson, Program Coordinator, University of Nebraska Medical Center, Continuing Nursing Education, 42nd and Dewey Avenue, Omaha, NE 68105-1065, tel: (402) 559-6417.

June, 1988

June 11: The *Blind Children's Center* will present the 1988 Margaret Bundy Scott Research Conference in Los Angeles on the topic: "Language Acquisition in the Visually Impaired Young Child: Theory and Practice." Write or call Patsy Rahn, Special Projects Coordinator, The Blind Children's Center, 4120 Marathon Street, P.O. Box 29159, Los Angeles, CA 90029-0159, tel: (213) 664-2153.

June 11-15: The *Association for the Care of Children's Health* will sponsor its 6th Annual Parent Network Meeting (June 11-12) and 23rd Annual ACCH Conference (June 12-15) in Cleveland, Ohio. The Parent Networking Meeting will feature a luncheon address by Kathleen Kirk Bishop. Lizbeth Vincent will speak to the conference on the topic "Parent-Educator-Health Professional: Partnerships for Care." Contact ACCH, 3615 Wisconsin Avenue N.W., Washington, D.C. 20016, tel: (202) 244-1801.

June 13-17: The *Frank Porter Graham Child Development Center* will hold its Annual Intensive Summer Institute in Chapel Hill, North Carolina. Participants can choose in-depth study of infant/toddler curriculum and environment with Thelma Harms; mainstreaming in infant and preschool education with Don Bailey, or state policy issues for P.L. 99-457 with James Gallagher. Write or call Pam Rolandelli, FPG Summer Institute, CB #8040, Suite 300 NCNB Plaza, UNC-Chapel Hill, Chapel Hill, NC 27599-8040, tel: (919) 962-7360.

June 17-20: The *Bank Street College Infant and Parent Development Program* will hold an institute in New York City for caregivers of infants and toddlers, directors of 0-3 programs, and other practitioners. The conference will be limited to 45 participants. Faculty will include Bernice Weissbourd, Ellen Galinsky, Ian Drucker, Virginia Casper, Nancy Balaban and Emily Schrag. For applications write to Nancy Balaban, Director, Infant and Parent Development Program, Bank Street College, 610 West 112th Street, New York, NY 10025.

June 20-24: *Syracuse University* will hold its 12th Annual Quality Infant/Toddler Caregiving Workshop in Syracuse, New York. The workshop will be taught primarily by Alice Honig and will include observations and interactions with infants and parents. Write or call Dr. Connor Walters, Administrative Assistant, Syracuse University, 201 Slocum Hall, Syracuse, NY 13244-1250, tel: (315) 423-2757.

June 22-24: *Contemporary Forums* will hold a conference in Washington, D.C. entitled "The Fetus and Newborn: State of the Art Care." Contact Contemporary Forums, 530 LaGonda Way, Suite E, Danville, CA 94526, tel: (415) 820-2800.

July, 1988

July 11-15, August 1-5: *Child Development Resources* will hold its Third Annual Early Intervention Summer Institute in July in Denver, Colorado and in August in Williamsburg, Virginia. The theme will be "Integrating Service Delivery: Policy, Ethics and the IFSP." Write to Child Development Resources, Inc., P.O. Box 299, 6325 Centerville Rd., Lightfoot, VA 23090.

July 26-31: *The Second Delphi International Psychoanalytic Symposium,* entitled "Maternal Configurations and Psychoanalysis: Clinical and Cultural Perspectives;; will be held in Delphi, Greece under the sponsorship of five Greek and Canadiaan organizations. Presentations by analysts, historians and sociologists will be featured. For information, write to Mrs. Chryssoula-Dora Gondicas, 19, Anagnostopoulou Street, GR-106 73, Athens, Greece.

August, 1988

August 7-13: The *International Institute for Visually Impaired, 0-7, Inc.,* will hold an international symposium in Edinburgh, Scotland. One major focus will be services for visually impaired children, including those with multiple handicaps, in rural areas and developing countries. For further information, write to Donna Heiner, IIVI, 07, Inc., 1975 Rutgers Circle, E. Lansing, MI 48223.

August 8-12: *Contemporary Forums* will sponsor a conference entitled "Perinatal Controversies" in Jackson Hole, Wyoming. Contact Contemporary Forums, 530 LaGonda Way, Suite E, Danville, CA 94526, tel: (415) 820-2800.

August 14-18: The *Institute for Integration* will sponsor the First International Conference on Family Support Related to Disability in Stockholm, Sweden. Topics to be addressed include cultural and ethnic aspects of family support, intervention programs, the impact of disability on family members, and research with families, among others. Write to The Institute for Integration, Normalmstorg 1, S-111 46 Stockholm, Sweden.

August 21-25: The *International Association for the Scientific Study of Mental Deficiency* will hold its 8th International Congress in Dublin, Ireland on the topic "Key Issues in Mental Retardation Research." Symposia will address high risk infants and mental retardation, early intervention, and the promise of gene therapy, among other topics. For information contact Brother Bernard Farrell, O.K., P.O. Box 1979, 532 Delsea Drive, Westville Grove, NJ 08093, tel: (609) 848-4141.

Zero to Three
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Individual Differences, Universal Needs: A 30-Year Study of Resilient High Risk Infants

by
Emmy E. Werner
University of California, Davis

> *"Every morn and every night,*
> *Some are born to sweet delight,*
> *Some are born to endless night."*
> *(William Blake, 1757-1827)*

Even under conditions of chronic poverty, in the most disorganized and discordant homes, and beset with serious physical handicaps, some infants develop into adults with stable and healthy personalities and display a remarkable degree of individual resilience. Such children have recently become the focus of attention of a multi-disciplinary group of researchers who have asked, "What is right with these youngsters?" and, by implication, "How can we help other children to become less vulnerable in the face of life's adversities?"

One of the largest and most comprehensive investigations to date that has explored the roots of resilience in young children is a prospective study of a multiracial cohort of 698 infants who were born in 1955 on a rural Hawaiian island. Beginning in the prenatal period, the Kauai Longitudinal Study has monitored the impact of a variety of biological and psycho-social risk factors, stressful life events, and protective factors on development at ages 1, 2, 10, 18, and now at ages 30 to 32.

The principal goals of the Kauai Longitudinal Study were to (a) document, in natural history fashion, the course of all pregnancies and their outcomes in an entire community from the prenatal period until the offspring reached adulthood, and (b) to assess the long-term consequences of perinatal complications and adverse early rearing conditions on the individual's physical, cognitive, and psycho-social development.

We need to keep in perspective that the *majority* of the infants in this birth cohort were born without complications, after uneventful pregnancies, and grew up in supportive home environments. But *one out of every three* infants could be considered "at risk" because they had experienced moderate to severe degrees of perinatal stress, were born into poverty, were reared by mothers will little formal education, and lived in a family environment troubled by discord, desertion or divorce, or marred by parental alcoholism or mental illness. *Three out of four* children in the *vulnerable* group (who

FLORENCE SHARP

This article was adapted from an address at the opening plenary session of the 5th Biennial Training Institute, National Center for Clinical Infant Programs, Washington, D.C., December 4, 1987.

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encountered four or more such cumulative *risk* factors *before the age of 2) did* subsequently develop serious learning and/or behavior problems by age 10 or had deliquency records, mental health problems, or pregnancies before age 18.

But, surprisingly, *one out of every four* of the high risk infants (30 M; 42 F)—some 10% of the total cohort—developed instead into competent, confident, and caring young adults. We subsequently began to look at roots of their *resiliency* and searched for protective factors within the individuals and their caregiving environment that appeared to ameliorate or buffer their responses to constitutional and stressful life events.

Protective factors in the lives of resilient children

Even as infants these individuals had temperamental characteristics that elicited positive attention from family members as well as strangers. Parents, visiting public health nurses, and social workers who made home observations at age 1 characterized a high proportion of these babies as "very active," "affectionate," "cuddly," "good-natured," and "easy to deal with." These resilient babies also tended to recuperate more quickly from illnesses and had fewer eating and sleeping habits which were distressing to their caretakers than the high risk infants who subsequently developed serious learning or behavior problems.

As toddlers, most of the resilient boys and girls tended to meet the world on their own terms. The pediatricians and psychologists who observed them independently during a developmental examination at 20 months, commented on their robustness, alertness, and responsiveness. Their mean scores on the infant examinations showed advanced communication and self-help skills relative to their more vulnerable peers.

Independent observers noted significantly more signs of autonomy and independence among the resilient toddlers, who were more often described by adjectives such as "aggressive," "determined," "dominating," "independent," and "stubborn" than high risk toddlers who later developed problems. The resilient toddlers were also characterized by a significantly greater number of adjectives that indicated a positive social orientation. Observers described them as "agreeable," "cheerful," "friendly," "responsive," and "self-confident" in interactions with *both* familiar caretakers and unfamiliar examiners.

These children had grown up in families with four or fewer offspring, with a space of two years or more between themselves and the next born sibling. Few had experienced prolonged separations from their primary caretaker during the first year of life. *All* had the opportunity to establish a close bond with at least one caregiver. The majority had received a great deal of positive attention from that person during the first year of life. Some of this nurturing came from substitute parents, such as grandparents or older siblings, or from the ranks of regular baby-sitters. The resilient children were especially adept at actively recruiting such parent substitutes, when their own mothers were incapacitated or absent.

For boys, being first-born was an important protective factor; for girls, the model of a mother who was steadily and gainfully employed. As disadvantage and the number of stressful life events increased, more protective factors in the children and their caregiving environment were needed to counterbalance the negative aspects and ensure positive developmental outcomes.

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FLORENCE SHARP

Objectives of the 30 year follow-up

When we last interviewed the members of the 1955 birth cohort at age 18, we were aware that the maximum period for mental breakdown was still ahead of the high risk youth. We did not yet know how well they would adapt to the demands of the adult world of employment, marriage, and parenthood (Werner & Smith, 1982).

Since 1985, we have been involved in a 30 year follow-up of the "resilient" high risk children, and of comparison groups of other high risk subjects who had previously developed problems (i.e., school failures, deliquencies, mental health problems, teenage pregnancies). Our follow-up has two general objectives:

(1) To trace the long-term effects of stressful life events in childhood and adolescence on the adult adaptation of men and women who were exposed to poverty, perinatal complications, and parental psychopathology, and

(2) To examine the long-term effects of protective factors (personal competencies, sources of social support) in childhood and adolescence on their adult coping.

The 30 to 32 year follow-up finds our cohort at a stage which provides the opportunity to reappraise and modify the initial mode of adult living that had been established in the previous decade. The Age 30 Transition period is biologically the peak of adulthood, a time of great energy, but also among the most stressful of the adult life cycle.

Methodology of the 30 year follow-up

During 1985-86, we located some 80% (N:545) of the survivors of the 1955 birth cohort. The majority still live on Kauai. Among them are most of the former "problem" children. Some 10% have moved to other Hawaiiian islands (Oahu, Maui, and Hawaii), most to Honolulu. Another 10% live in the U.S. mainland, some 2% live abroad. Among those who moved away from Kauai are most of the resilient individuals.

Our follow-up at age 30 combines the use of our previous data base from infancy to late adolescence with an assessment of the individual's adult status via structured interviews, questionnaires, and community records. The interview assesses the cohorts' perceptions of major stresses and sources of support in their adult lives: In school; at work; in their relationships with their spouses or mates, their children, parents, in-laws, siblings, and friends. It concludes with a summary assessment of the person's state of health, satisfaction, and well-being at the present state of life. In addition, we have access to the court records on Kauai and the other Hawaiian islands. They contain criminal, civil, and family court files which are open to the public and cover the period since our last follow-up at age 18.

So far, we have data on every member of the 1955 birth cohort with a criminal record (N:31) or with a marriage that ended in divorce by age 30 (N:70). We also have a follow-up data on 72% of the resilient subjects (N:52) and on the majority of the former deliquents, the youth with mental health problems, and the teenage mothers.

Stressful life events in early childhood that significantly increased the likelihood of crime or divorce by age 30

More than half of the stressful life events that significantly increased the likelihood of having a criminal record or an "irrevocably broken marriage" by age 30 for members of this cohort took place in infancy and early childhood. Among such stressful life events that had negative effects on the quality of adult coping for *both* men and women were:

(1) the closely spaced birth of a younger sibling in infancy (less than 2 years after birth of the index child);
(2) being raised by a mother who was not married at the time of the child's birth;
(3) having a father who was permanently absent during infancy and/or early childhood;
(4) experiencing prolonged disruptions of the family life and separations from the mother during the first year of life (that included unemployment of the major breadwinner, illness of the parent, major moves) and
(5) having a mother who worked without adequate substitute child care during the first 20 months of the child's life.

A significantly higher proportion of males with a criminal record (that included promotion of harmful drugs, theft and burglary, assault and battery, rape and attempted murder) experienced such disruptions of their family unit in their early years, as did the men and women whose marriages had ended in divorce by age 30.

The resilient men and women in their early thirties

Let us now briefly examine the adult status of the "high risk" infants who had previously coped successfully with poverty, parental psychopathology, and disruption of their family unit in childhood and adolescence. These individuals had graduated from high school during the height of the energy crisis and had joined the work force during the worst economic recession in the U.S.A. since the Great Depression. But, in spite of these economic constraints, most are coping well with the demands of one of the most stressful periods in the adult life cycle. Even though some have continuing worries about problems of family members and finances, three out of every four of these resilient individuals consider themselves happy or satisfied with their current status in life.

Both the men and women are highly achievement oriented. With few exceptions, they have pursued additional education, and are currently in full-time employment, the women predominantly in semi-professional and managerial positions, the men either in skilled trades and technical jobs or in the professions. Four fifths of the men and three quarters of the women are satisfied with their present employment status. The majority of the men and women list "career or job success" as their primary goal for themselves at this stage of life, outdistancing other objectives such as a happy marriage, children, or close relations with friends and family.

The women in this group have made more transitions into multiple life trajectories than the men. Eighty-six percent are married, have children, *and* work full-time. In contrast, only half of the men are married and have children. There appears to be a greater reluctance among the males in this group to make commitments to marriage, or to remarry when their first marriage ends in divorce. A higher proportion of the males than the females report that the breakup of a long-term relationship between the ages of 18 and 30 has been a source of great stress to them. The expectations from a marriage or a long-term relationship also differ significantly by gender. The majority of *both* males and females want permanency and security from marriage, but a much higher proportion of the women expect intimacy and sharing from such a relationship.

For those who are parents, the primary goals for their children is the acquisition of personal competencies and skills. A significantly higher proportion of the resilient women than the resilient men expect high achievement from their children. A higher proportion of the women also stress early independence in their offspring, while a higher proportion of the men tolerate dependence in their young children.

The majority of the resilient men and women at age 30 consider their personal competence and determination to be their most effective resources in coping with stressful events in their lives. Both sexes also value the support of a mate. But the resilient women draw on a significantly larger number of additional sources of support than the men that include faith and prayer, friends, relatives, siblings, and co-workers. In contrast, the resilient males appear to rely almost exclusively on their own resources, with some additional support from spouses or parents. They derive emotional support from friends and siblings less frequently, and co-workers more often are considered sources of stress for them.

It appears from this preliminary analysis of our interview data that the competence, determination, and internal locus of control displayed by these resilient individuals are relatively enduring characteristics that have enabled them not only to overcome a difficult infancy, childhood, and adolescence, but also to cope successfully with transitions into adult responsibilities. But, as in previous decades, the resilient women tend to weather stressful life events with fewer impairments to their health and fewer psychosomatic or "internalizing" symptoms than the men, and they also recruit and draw on more sources of social support.

Summary and conclusions

Three relatively enduring constellations of "protective" factors emerge from our analyses of the developmental course of the children of Kauai. They include (1) dispositional attributes of the individual that have a strong genetic base, such as activity level, sociability, and intelligence; (2) affectional ties within the familiy that provide emotional support in times of stress, either from a parent, grandparent, sibling, mate, or spouse, and (3) informal support systems at school, work, and/or church that reward the individual's competencies, provide a sense of meaning, and foster an internal locus of control. Such protective factors appear to have a more generalized effect on adaptation in childhood, adolescence, and young adulthood than specific risk factors or stressful life events. They may also have more cross-cultural universality than risk factors that lead to pathology in a given culture.

What determined the range of developmental outcomes that we encountered in the children of Kauai was not a single risk factor, but the *balance* between pre- and perinatal risk factors and stressful life events which heightened children's *vulnerability* and the protective factors in their lives which enhanced their *resiliency*. This balance shifted with the stages of life cycle and varied also with gender and cultural context. As long as the balance between stressful life events and protective factors were manageable for an individual, s/he could cope. But when stressful life events outweigh the protective factors in life, even the most resilent child can develop problems.

Interventions may thus be conceived as an attempt to shift the balance from vulnerability to resilience, either by decreasing exposure to risk factors or stressful life events, or by increasing the number of available protective factors (e.g., competencies and sources of support) in the lives of vulnerable children.

Implications

What then are some of the implications that we can draw from our findings for early intervention? It needs to be kept in mind that our research on individual resilience and protective factors has focused on children who "muddled through" on their own, with informal support form kith and kin, *not* children who were recipients of early intervention services. Yet, there are some lessons such children can teach us about early intervention.

(1) There are large individual differences among "high risk" children in response to *both* negative and positive circumstances in their environment. The very fact of individual variation among infants and young children who live in adverse conditions, suggests the need for greater assistance to some than to others.

(2) These results alert us to the need for setting priorities, to choices that we must make, if we cannot extend early intervention services to *every* child from birth to three years of age. Such programs need to focus especially on infants and young children who appear most vulnerable and at high risk for developing problems in adulthood because they lack some of the essential social bonds that appear to buffer stress. Among those whose numbers have been on the increase in the U.S.A. in recent years are: Young children who live in chronic poverty; the offspring of substance-addicted parents; infants and toddlers whose mothers work without access to adequate child care; the young children of single and teenage parents, with no other adult in the household; and young children without any permanent roots in a community—the migrant and the homeless.

(3) Assessment and diagnosis, the initial part of early intervention, need to focus not only on the risk factors, but also on the competencies and sources of informal support that *already* exist in children's lives and that can be utilized to enlarge their repertoire of problem solving skills and to enhance their self-esteem.

(4) In order for any early intervention program to be effective, a young child needs enough consistent nurturance to trust in its availability. Our research on resilient children has shown us that they had at least one person in their lives who accepted them unconditionally, regardless of temperamental idiosyncracies, physical attractiveness, or intelligence.

(5) Our research on resilient children has also shown that if a parent is incapacitated or unavailable, other significant people can play such an enabling role, whether they are grandparents, older siblings, family day care providers, or nursery school teachers. In many situations it may make better sense to strengthen such available informal ties to kin and community than to introduce additional layers of bureaucracy into the delivery of services for high risk children—and it might be less costly as well.

(6) The fostering of resilience in young children by caring adults does not rely on removing stress and adversity completely from their lives, but rather in helping them encounter graduated challenges that enhance their competence and confidence.

(7) While our studies show that some youngsters are constitutionally more resistant to stress than others, *all* children can be helped to become more resilient if their caregivers encourage their independence, teach them flexible ways of problem solving (including appropriate communication and self-help skills), boost their self-confidence, and model as well as reward acts of helpfulness and cooperation.

The life stories of the resilient children of Kauai have taught us that competence, confidence, and caring can flourish, even under adverse circumstances, if young children encounter persons who provide them with a secure basis for the development of trust, autonomy, and initiative. Evaluations of effective early intervention programs can, in turn, illuminate the process by which the chain of direct and indirect links among protective factors is established, which fosters escape from adversity for vulnerable children.

Bibliography

Werner, E.E., & Smith, R.S. (1982). *Vulnerable but invincible: A longitudinal study of resilient children and youth.* New York: McGraw-Hill.

Werner, E.E. (In press). Protective factors and individual resilience. In S.J. Mosels and M. Shonkoff (eds.), *Handbook of Early Intervention.* Cambridge University Press.

Correction:
In the February, 1988 issue of *Zero to Three*, **the dedication of Lucial Nerenberg's case study on page 11 should have read, "Dedicated to the memory of a dear friend, Anita D. Baker."**

Enduring Gains: A Five-Year Follow-Up Report on The Clinical Infant Development Program

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Infants and parents in multirisk families can benefit from persistent, in-depth, long-term treatment approaches. Moreover, positive changes in the lives of parents and young children across a range of domains tend to be sustained or even amplified five years after the ending of such an intensive service program.

These are the major findings of a five-year follow-up study of 32 multi-risk families who received intensive, comprehensive services through the Clinical Infant Development Program (CIDP) of the National Institute of Mental Health.[1] From 1977 to 1983, CIDP undertook to identify those clinical techniques and service delivery models which might conceivably succeed in reversing maladaptive patterns in multiproblem families; the study hoped to develop approaches that would help very young children to build on existing strengths and coping capacities and to experience success as they grew. The Clinical Infant Development Program was initiated and supervised by Stanley Greenspan, Reginald S. Lourie, Robert Nover, and Mary Robinson of the National Institute of Mental Health; the work took place in Prince Georges County, Maryland, outside Washington, D.C., under the direction of Serena Wieder.

During the six years of its existence, CIDP recruited 47 high-risk pregnant women, all older than 18, who had at least one other child. Twenty-seven of these families received intensive, comprehensive services, including the organization of concrete assistance, a constant emotional relationship, and specialized developmental and psychotherapeutic services to infant and parents. During the last three years of its grant, CIDP also recruited 15 pregnant adolescents younger than 18. The findings reported here come from the follow-up of 32 of these families (19 adults and 13 adolescents) after the end of the CIDP intervention program. We will also describe a community-based comprehensive service model, designed to meet the needs of infants and families through an early intervention and prevention approach, which reflects our growing understanding of family needs during the 1977 to 1983 study.

Not everyone's problems have been solved or every life struggle alleviated in the 32 follow-up families, but we do continue to see enhanced self-esteem, purpose, and self-reliance in family after family who have taken responsibility for their lives five years after our contacts. We see children who are not repeating developmental failures of their older siblings, who are able to reach out and make use of other people and relationships rather than withdraw or become aggressive, and who can learn and stay "on track" in school rather than repeat failure.

Our analysis of the experiences of families in the CIDP suggests a number of program features that may account for the improved coping of parents and children.

- Preventive intervention approaches which were not based on preconceived notions of who responds well to therapeutic efforts;
- Persistence and pursual by intervenors to learn more about the therapeutic process, particularly the meaning of flight, rejection, anger, and other patterns of negative relationships;
- Multidimensional approaches which allowed families to respond to the services they could use at the time, including home visits, the Infant Center, concrete support, individual and group therapy, and social and educational activities;
- An intervention team with two key workers who could represent interactive relationships, stay engaged with the family when relationships with one or the other of the team became too threatening, keep focused on the infant and family relationship, and support each other;
- Identifying specific patterns of care and intervention to meet the individual needs of infants (e.g. low motor tone, distractability, withdrawn), helping them to be more responsive and interactive with their parents;
- Long-term involvement which supported and enriched each child's development through the significant early years of life and provided a sustained therapeutic relationship with the parents to permit healing and the development of a capacity for trust, intimacy, and self-esteem;
- An approach to "parenting" which was based on mutual engagement, reading and responding to needs and signals, tolerance of negative feelings, limit setting, and the progressive organization and symbolization of behavior and feelings.

Parents and infants at entry, outcome, and follow-up

Tables 1, 2, and 3 summarize the changes in characteristics of adult and adolescent parents between entry, outcome, and follow-up. It must be remembered that mothers were recruited into the program because

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[1] The Clinical Infant Development Program is described in detail in NCCIP's third Clinical Infant Report, *Infants in Multirisk Families*, edited by Stanley Greenspan, Serena Wieder, Alicia Lieberman, Robert Nover, Reginald Lourie and Mary Robinson and published by International Universities Press, Madison, Connecticut, in 1987. The volume describes the organization of the service program and its research tools and methods, including the "index of misfortune"; four in-depth case studies document the clinical work with infants and families.

Table 1

Entry Characteristics of the Parents in Follow-Up

	Age (Yrs.)		Race	
	Range	X	Black	White
Adult Parents (N=19)	19-35	24.7	63.1%	36.9%
Adolescent Parents (N=13)	15-17	16.5	76.9%	23.1%

Table 2

*Changes in Characteristics of Adult Parents Between Entry, Outcome, and Follow-Up**

	Entry	Outcome	Follow-Up
Regular Health Care Obtained	5.3%	52.6%	100.0%
Psychiatric Hospitalization	31.6%	0%	10.5%
Regular Use of Birth Control	0%	52.6%	94.7%
Education Level—H.S./GED	47.5%	57.9%	57.9%
Employed	21.1%	42.1%	57.9%
Receiving Public Assistance	57.9%	31.6%	31.6%
Married/Ongoing Relationship	26.3%	31.6%	42.0%
Additional Births:			
—within marriage/long-term relationship	N/A	26.3%	15.8%
—outside stable relationship	N/A	5.3%	5.3%
Reports of Abuse:			
of parent	68.0%	14.0%	5.3%
of child	47.6%	0%	0%

*N=19

Table 3

*Changes in Characteristics of Adolescent Parents Between Entry, Outcome, and Follow-Up**

	Entry	Outcome	Follow-Up
Regular Health Care Obtained	15.4%	84.6%	84.6%
Regular Use of Birth Control	0%	69.0%	76.0%
Education Level—H.S./GED	0%	15.4%	30.8%
Employed	7.7%	46.2%	76.9%
Receiving Public Assistance	7.7%	76.9%	0%
Married/Ongoing Relationship	7.7%	23.0%	46.2%
Additional Births:			
—within marriage/long-term relationship	N/A	15.4%	30.8%
—outside stable relationship	N/A	7.7%	7.7%

*N=13

they were already demonstrating substantial difficulty in caring for at least one child and were pregnant with another. As we got to know these women, we learned that they had experienced stresses such as abuse in childhood, battering as an adult, loss of significant others, school failures, and psychiatric hospitalizations—among the older mothers, an average of nine items per person on what we termed an "index of misfortune."

The infants born to CIDP mothers were healthy at birth, but the experiences of their older siblings suggested that their development was likely to become significantly delayed or distorted during the first three years of life unless positive changes in the nurturing environment occurred. Table 4 summarizes the current status of project children, now between 5 and 10 years old, with respect to school placement, social participation, and the presence of emotional difficulties.

CIDP goals and approaches

In order to understand the meaning of parent and family outcomes, it is important to consider what the intervention program hoped to accomplish. In an effort to reverse maladaptive patterns which in some cases had persisted for generations, CIDP attempted to develop new, integrated approaches to serve families who had not been able to use traditional and often fragmented services available in the community. The model of intervention was based on two primary assumptions.

- It is necessary to address multiple lines of development during early intervention. This involves not only supporting the emotional, cognitive, sensory, and physical aspects of development simultaneously, but supporting development in stage-specific ways.
- The infant must be addressed in the context of the family, including the mother, father, other family members and mother-relevant social structures. Intervention must address the parents' predominant attitudes, feelings, and family relationships, and other crucial factors such as health and mental health.

Three components made up the CIDP intervention model:

1. Organizing basic services for adequate food, housing, medical care and educational opportunities, to deal with day-to-day survival and future family stability;
2. Providing a constant emotional relationship with the family through which trust could be established with the parents and the infant; and
3. Providing specialized services to the infant and parents geared to meet the challenges at each stage of development, given each infant's and parent's individual vulnerabilities and strengths.

These three basic service components also defined the outcome variables we selected to follow at the conclusion of the program. We will first address how families have fared with respect to their ability to function independently and improve the quality of their day-to-day lives. Secondly, we will address their relationships with their children, their families, other social supports, partners, and sense of self. Third, we will look at how the children have done in school with respect to cognitive and academic performance, social and emotional development, and adaptation to age-appropriate demands and activities.

Independent functioning in daily life

Families recruited into CIDP not only had difficulty supporting their infants but also in sustaining themselves. We recognized that our first job was to deal with basic survival and sustenance. Staff spent many hours helping families to get WIC benefits, food stamps, housing, and public assistance. We learned what it was like to be evicted, to wait in emergency rooms, and to face crisis after crisis as a way of life. We saw these experiences as opportunities to reach out and develop relationships with our participants. We joined our mothers and tried to help them experience alternatives as we mediated better solutions, supported taking chances, and went through the steps to develop skills and judgment.

For most of our families these lengthy efforts paid off by the time we ended our program, and even more so in subsequent years. Five years after the intervention program ended, three times as many of the adult mothers are employed as had jobs at entry and only about half as many are receiving public assistance. Although some change in this direction would be expected after ten years, the trend for this highly impacted population is to get worse as repeat pregnancies ensue and family functioning deteriorates. Furthermore, seven of the eight mothers who were not working were raising four or more children at home. While adult mothers did not as a group significantly increase their level of formal education, they did obtain job training. They are working in day care, business offices, and charity organizations, some in a supervisory capacity. None of the adolescent mothers had graduated from high school or obtained a GED certificate at entry to the program; at the 5-year follow-up, 31% had achieved this educational level. A remarkable 77% of the adolescent group are employed, and an additional 15% are working at home raising their children within family relationships. None are receiving public assistance.

The economic improvement of CIDP participants may be in part due to the fact that the small number of repeat pregnancies has meant increased freedom to work outside the home and fewer children to support with available resources. Only six of 27 adult mothers had more children during the course of the six year intervention program and only three had children in the following five years, two of those in the context of marriages. Within the adolescent group, three women had another child during the two year program. Two of these were planned within marriage and the third was placed in foster care. In the five year follow-up period, four more had additional children as part of marriage or a lasting relationship, as might be expected of women now in their twenties. Two of these births occurred in the same families noted above, a third in a new marriage, and the fourth to a single parent who lives with a supportive family.

We believe the remarkably low birth rates reflect CIDP's efforts to strengthen mothers' attachments to and investment in their existing children and to increase their success and self-esteem as parents and as people. For some mothers it was our impression that repeat pregnancies were an attempt to deal with a sense of failure with their existing children. Consistent with this hypothesis, 84.6% of former participants in both adult and adolescent groups report active use of birth control and 93.9% obtain regular health care for themselves and their children five years after the end of the program.

Developing trusting relationships

Developing trusting relationships, the second goal of the Clinical Infant Development Program, presented our greatest challenge. The adult mothers in the group had all suffered significant trauma and failures throughout their lives, as captured in our "index of misfortune." Our initial assessments revealed a population of severely fragmented and depressed women, some with impaired reality testing and/or very low adaptive functioning, and all seriously compromised in their ability to provide protective environments, develop intimacy, and read and respond to their infants' cues. Except for psychiatric hospitalization, however, these women did not make use of traditional mental health services. Nevertheless, we believed that a sustained therapeutic relationship with CIDP staff would be the critical factor in bringing about change. If we could develop trust and provide an ongoing relationship which could be a basis for intimacy and which would help these mothers develop closeness with their children, enduring change might be possible, and mothers' commitment to these children would continue after we were gone.

Our faith in this premise waivered more than once during six years, but we persisted. Many women were very resistant to contact with us, highly suspicious, enraged, terrified of closeness, and therefore unable to sustain any relationships. Objective ratings at the end of one year of intervention showed little change. The gains evident at outcome came *after* one year. Even when they were suspicious of us and missed appointments, we persisted in reaching out. Parents considered resistant were seen as many times as the cooperative parents because of outreach efforts.

We believe that it was the staff's persistent pursual and remarkable ability to tolerate rejection and suspiciousness that allowed many mothers to "work through" their earlier disappointing relationships, a necessary step before they could go on relating to and eventually "talk" to us about their feelings. We recognized that participants' ability to engage in appropriate relationships and to maintain their self-esteem would certainly be tested by the passage of time.

Table 4

Current Status of Children

	Age (Yrs)		Sex		IQ		Reg. School	Social*	Emotional
	Range	X	Female	Male	X	S.D	Placement	Participation	Difficulties
Children of Adults (N=27)	6-10	7.8	34.1%	65.9%	104.2	18.1	85.2%	54.2%	14.8%
Adolescents (N=14)	5-7	6.2	46.2%	53.8%	99.2	13.6	76.9%	41.7%	15.4%
Overall (N=41)	5-10	7.3	48.8%	51.2%	102.6	16.8	82.9%	50.0%	14.6%

*Involvement in team sports and local youth organizations, i.e., scouts.

Five years after the intervention ended we found 42% of adult mothers married or in sustained relationships. Further, the quality of these relationships had improved, as evidenced in the decrease in spouse abuse, from 60% to 5.3% for the older mothers and from 50% to 18% for the adolescents. Similar improvements have occurred in the quality of the parents' relationship to their children; nearly half of the older mothers had physically abused their children prior to entry and *none* have abused since. Of the parents who were single at outcome and continued to be at follow-up, we heard improved judgment and appropriate behavior with regard to relationships.

The longer adult mothers participated in CIDP the better they did at outcome and follow-up, as reflectd by objective clinical ratings at outcome and self-reports and observations at follow-up. Engaging, developing relationships, and forming attachments is a process which may take as much time in intervention programs as it does in real life. When relationship capacities are compromised by distrust and repeated failures, it is the long term experience of a different kind of relationship, i.e., therapeutic, which finally allows for change. Those mothers who needed to reenact disappointing or hurtful experiences with us took longer to involve positively, but we understood their rejection and anger, directed it towards us, and could in this way sometimes help them be more available to their children. When we had to end the intervention program at the termination of our grant period, staff hoped that some mothers would continue in some form of therapy. In fact, only one mother sought further formal therapy for herself during the five years that followed. Seventy-three percent of mothers, however, report many new friendships and improved relations with their families during this period. Participants also report using community-based supports, such as churches.

The adolescent mothers, who averaged 22 years of age at the five year follow-up, also did well in their relationships within and outside the family. Half of the 13 are in stable relationships with partners, four with the fathers of the children with whom they were pregnant at the time of entry into the CIDP. Three of the young women are married. Although 5 of the mothers currently without partners report positive supportive relationships with friends and family, two continue to struggle in this domain. From clinical reports it seems that those adolescents who were resistant to engage initially but who "battled things out" with their therapists ultimately achieved better relationships with their families than those who were compliant with therapists.

The significantly higher number of adolescent mothers (86.7% vs. 70% adult) who have continued follow-up speak to the critical timing of outreach and early intervention with pregnant adolescents who need support at this turn of their lives and who continue these contacts. Even three teen mothers who could not sustain the care of their children had their families take over and have maintained their contacts with their children who live with grandmothers and grandfathers.

The children: an opportunity for prevention

The children in the program gave us the opportunity to test the impact of preventive intervention. Their progress five years after the end of the program is summarized in Table 4 and has been determined in several ways: by major shifts in test results (from one standard deviation to another), by continued placement in regular school classes, by movement from special education to regular classes, and by improved sense of self.

Most of the children involved in CIDP (87.8%) were healthy at birth, but as they grew, differences both in physical adaptation, (e.g. hypersensitivity to touch or sound) and in the nurturing abilities of their parents resulted in varying patterns of development. One group of children (n=15) showed consistent cognitive growth; these children sustained average levels of functioning during the follow-up period. Another group (n=17) showed more vacillation in cognitive development, suggesting more vulnerability and reactivity, during the program years. These children were, however, in the average range of cognitive functioning when CIDP ended and continued to be so five years later. Currently, only 17.1% of the children (n=7) are receiving special education services; their parents sought these services out, and were able to accept recommendations for further help. Considering that 49% of the parents in the program experienced impaired functioning in school, many children have succeeded in doing better academically than their parents. Early referrals to therapeutic pre-school programs for 36.6% of the children appeared to help in preventing special education placements beyond kindergarten.

The most recent test results of the children's cognitive development reveal that 80.5% are in the average range and above (within one standard deviation of the mean), based on WISC-R or McCarthy, depending on the child's age. Of this group 15.3% are one standard deviation above the mean. Comparing the individual's most recent test results with those at the end of the intervention, 87.8% have either maintained or improved their cognitive performance level. It is noteworthy that the five children whose test results have decreased were children born late in the program who received services for only about one year.

While improvements in cognitive test results are impressive (as measured through periodic assessment), those scores alone present a limited view of a child's overall functioning. The child's ability to form meaningful relationships, to cope with life stresses, and, most important, to experience life as positive and rewarding are also critical. One indicator that appears to be pivotal in increasing children's sense of self and self-esteem is their later participation in non-academic activities such as team sports, dance, and church-sponsored functions for young people. Approximately 50% of project children were involved in such an activity at the time of follow-up.

Behaviorally and emotionally, most of the project children are functioning well. According to reports obtained in structured interviews from parents regarding their children's behavior and personality, all but 6 children seem emotionally healthy. Four of these six appear to be mildly depressed; one has a conduct disorder and a family history of severe psychopathology on both sides; and the last was born with serious medical complications, was abused by his father, and now receives special education and counseling services. Fifteen reports received from teachers on the Zeitlin Coping Inventory indicate that the children are adapting to the demands of the school and to the demands that are self-imposed. Ratings of adequate functioning have been received for children in special placement as well as those in regular settings. Additional analyses are underway using the Achenbach Child Behavior Checklist and Profile, to be reported shortly. The resulting profiles will indicate behavioral problems and competencies of the children in a standardized manner.

The overall emotional, behavioral, and cognitive status of the children suggests that the children who received early intervention developed good ego functions; they are intelligent, achieve in school, show good impulse control, are engaged socially, and evidence warmth, closeness, and a wide range of affect. The children appear to have reversed the patterns we saw in their parents and their siblings. The tendency towards depression, noted in four of six children having difficulties, rather than acting-out, suggests higher levels of ego structure and personality development, and is more responsive to change.

Predicting outcome

After reviewing the initial presenting data on the 39 high-risk mothers who were to receive intensive, comprehensive services from CIDP, independent raters tried to predict who would benefit from the program. They could not. These mothers did not appear bright, insightful, or motivated; they lacked all the typical indicators for good therapy outcomes.

When we assessed who had made the most gains during the program on independent, objective clinical rating scales (included in the appendix to *Infants in Multirisk Families*), mothers considered "cooperative" by the staff attained the highest scores, but the mothers at greatest risk had made the most *progress*. This outcome may have been due to staff commitment to pursue and persist with all mothers in the program; the "resistant" mothers were seen no less often than the "cooperative" participants.

Follow-up issues

Two-thirds of the comprehensive intervention group remained in the follow-up for five years. Of the third who dropped out, four are known to have moved out of the area and two we have not been able to reach. In order to examine possible bias favoring those mothers who stayed in, we looked at previous hospitalization and diagnosis to see if the drop-out mothers were more severely impaired. A third of each group, i.e., those who stayed or dropped out of the follow-up, had been hospitalized and the severity of diagnoses (DSM III) does not appear different.

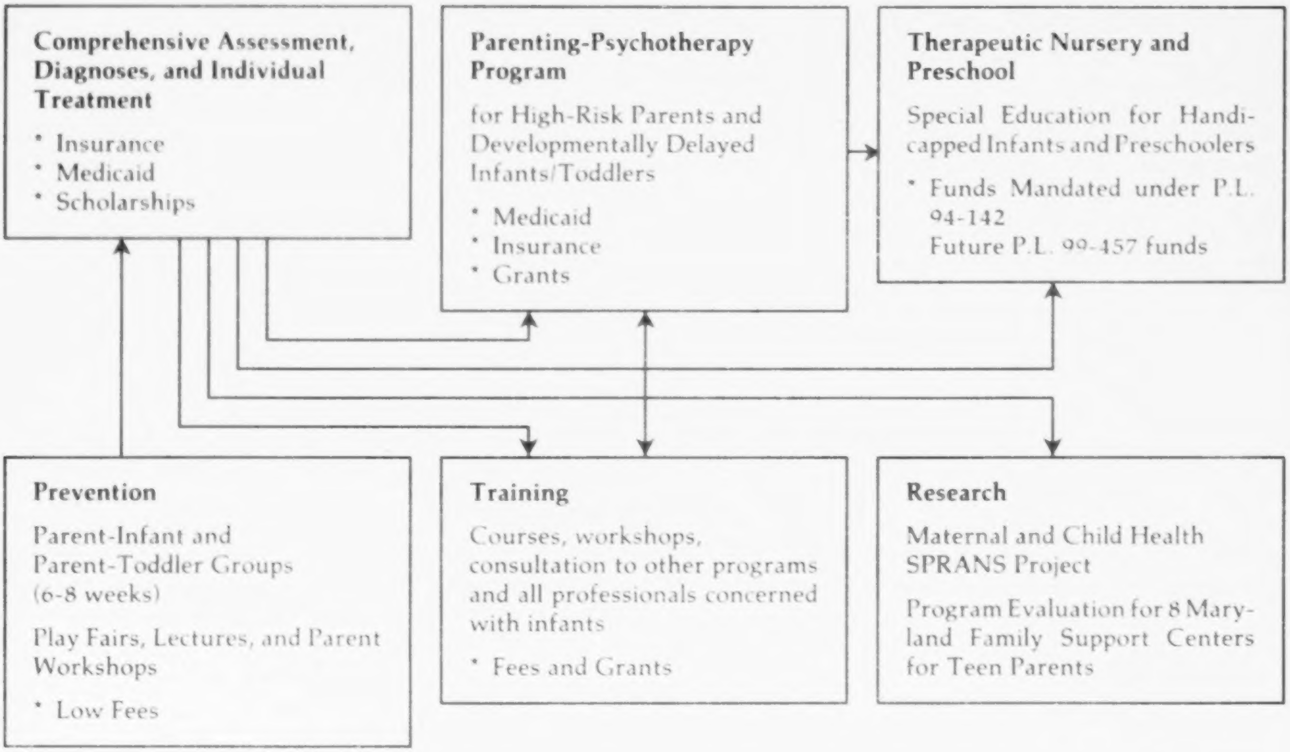
A comparison study was part of the initial design and alternative assignments to intervention and comparison groups were undertaken. However, only 17 participants were assigned in this fashion. They were to be seen for periodic assessments, consultation, and referral for services. During the first year of participation, eight assessments were conducted and contact with most families was maintained. Initial data analysis indicated mothers and babies in this comparison group were different at entry or at birth from the intensive group. After the first year assessments were only conducted twice a year and we began to lose more and more comparison families. A few returned at outcome when offered funds for their time, but none have been seen since. These families have continued to move frequently, never followed through on referrals, and could not be located through the agencies where they were first identified. The limited services offered (assessment, consultation, and referral) were unfortunately insufficient or not meaningful enough to engage and form more lasting relationships with these families. Some became angry when they realized others got more, appropriate community services were not really available, and staff found it difficult to pursue these families without being able to provide help needed.

An ongoing program

When funding for the original Clinical Infant Development Program completed its planned cycle after six years, its sponsors and staff were not willing to

Table 5

Regional Center for Infants and Young Children
of Washington, Maryland, and Virginia
Model Services Programs



Comprehensive Assessment, Diagnoses, and Individual Treatment

- * Insurance
- * Medicaid
- * Scholarships

Parenting-Psychotherapy Program

for High-Risk Parents and Developmentally Delayed Infants/Toddlers

- * Medicaid
- * Insurance
- * Grants

Therapeutic Nursery and Preschool

Special Education for Handicapped Infants and Preschoolers

- * Funds Mandated under P.L. 94-142
  Future P.L. 99-457 funds

Prevention

Parent-Infant and Parent-Toddler Groups (6-8 weeks)

Play Fairs, Lectures, and Parent Workshops

- * Low Fees

Training

Courses, workshops, consultation to other programs and all professionals concerned with infants

- * Fees and Grants

Research

Maternal and Child Health SPRANS Project

Program Evaluation for 8 Maryland Family Support Centers for Teen Parents

All programs address the emotional, developmental, and family needs, providing integrated mental health, speech and language, OT, PT, and parenting interventions.

*Funding provided by these resources.

let the program die and began to plan ways to continue efforts. In addition to publishing what we had learned from our experience, we also used this knowledge to develop a comprehensive service model for young children and families. We constructed a model designed to be flexible enough to address a variety of family needs and developmental problems, to embrace a prevention focus, to avoid fragmentation of service delivery, and to take advantage of every form of funding resource available to support the development of infants, children, and their families. In 1983 we were able to establish the Regional Center for Infants and Young Children, a private, non-profit program that offers integrated approaches to early intervention through the use of multidisciplinary teams and the organization of different levels and intensities of services to meet varying infant and family needs. The Regional Center, supported by fees, state and local grants, the federal Office of Maternal and Child Health and foundations, shares knowledge from its clinical service and research programs through a variety of training programs. Table 5 identifies the various components of the Regional Center model and the sources that fund each type of service.

In conclusion

Our five year follow-up of participants in the Clinical Infant Development Program supports the view that gains from therapy become evident after the therapy is completed. The achievements of project families, who could so easily have succumbed to defeat, are remarkable. So are the accomplishments of CIDP staff, who truly dedicated their lives to engaging deeply troubled families in every way they could, on the family's terms, building lasting trust.

As the implementation of federal legislation directed toward enhancing the development of infants, toddlers, and their families and of large-scale preventive intervention efforts funded by public and private resources brings new challenges, CIDP's follow-up findings suggest that the challenges presented by these programs can be met. The nation's youngest citizens and their parents not only deserve our best efforts, but our efforts can make a difference.

Individual Differences, Unique Needs: Two Teen Parents in the Clinical Infant Development Program

Cindy and Margaret convey how different two teen parents can be. They shared certain adolescent struggles but were in very different risk categories, requiring different levels and kinds of intervention. It is crucial to make these distinctions in working with young teen parents in order to persist with those who need in-depth and long-term efforts.

Margaret is an attractive, well-groomed, 23 year old with a husband and two children, ages 2 and 6 years. She has worked for a government agency for 3 years and she speaks of "moving ahead", hoping to specialize in personnel work. In fact she has just had two interviews with a local research hospital. "I've only started to look; I know I'll find it within the next few months." While she now has a family, a stable home life, and a job, 7 years ago she shocked her parents when she became pregnant. She had never done anything "wrong" before in their eyes; this easy child who was a good student, always came home immediately from school, never hung around, never took drugs and would never have sex. Behind this "perfect" facade was an adolescent struggling with identification and separation. When her father left town for a short trip she got pregnant. Several deaths had also recently occurred within the family.

Margaret's mother had also been pregnant at 17. Fortunately, Margaret's mother, who remembered her guilt and embarrassment at being pregnant, even though married, felt compassion for her teen daughter who would go through this pregnancy without a partner. She worried about Margaret's tendency to be a loner and "stay in." She encouraged her participation in CIDP where she would get support from peers and therapy to understand the meaning of her pregnancy and her underlying fears of separation. She too would have someone to talk to.

As Margaret's baby grew and became mobile, her fears and depression heightened as well. Counseling sessions were more frequent and feelings of guilt and shame could be addressed. As she understood more about herself, she began to encourage her son's precocious advancement. Both have gone on to successful and happy lives.

Life for Cindy is driven by getting drugs and being high. Only five years ago she appeared to be a young happy and carefree teen, in the 9th grade. The true story is very different. She was abused at an early age and frequently witnessed violence and drug use among family members. Psychiatric hospitalizations of her half-sister, sister, and brother were repeated in this family of five children and one parent. But Cindy is the baby and continues to have child-like qualities (giggly, pretty, and compliant) even today.

Cindy's father is a missing piece in the puzzle. Her mother refers to herself as Mrs. Kent but never speaks about a husband, nor does Cindy. At 15 Cindy got pregnant at the same time of her sister's first pregnancy. The timing is unclear as to who was first, but feelings of jealousy and competition were longstanding and characteristic of everyone's neediness. Grandmother and Cindy also fought over who would be the baby's mother. Grandmother insisted, "Tonight the baby sleeps with me, the next night with you." Intervention efforts are impeded as Grandmother is jealous of Cindy's therapist and paranoid of what will be revealed. As Cindy becomes more attached to the therapist she finds out more about herself and her capacities. Her sense of self, separate from her mother's, begins to emerge. The process is long; she's been submerged and enmeshed in her mother's personality. Mrs. Kent is an older woman who has been diagnosed as phobic and having subtle paranoid tendencies. Just as Cindy stops being a giggly, compliant, little girl and digs deeper, the program is ending, an end that is premature. An end that means separating permanently from the first person who Cindy felt valued her. She was only beginning to understand that beyond her family, life is not always chaotic and a crisis. The counselor helped her get into night school and was teh substitute parent who accompanied her to the teacher conferences. All was in place—and then Cindy panicked as the time to say good-bye neared. Another pregnancy ensued, perhaps an attempt to hold onto the person who had done so much.

More Pride, Less Delinquency: Findings from the Ten-Year Follow-Up Study of the Syracuse University Family Development Research Program

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The findings were dramatic, and captured the attention of *The Washington Post, The London Times,* and *The Los Angeles Times:* Ten years after their participation in the Syracuse University Family Development Research Program, children had a 6% rate of juvenile delinquency compared to a 22% rate for children in a control group. Not only was the control-group delinquency rate almost four times greater, but the offenses were much more severe. Of the four program-group children with probation records, three were charged with simple unruliness and the fourth with one-time juvenile delinquency. In contrast, of the 12 control-group children with criminal records, five were chronic offenders; control children committed acts of burglary, robbery, physical assault, and sexual assault. In addition, the cost to the court and probation department for handling the cases was estimated at $12,000 for the program group and $107,000 for the control group.

Our findings—associating high quality early education and family support with reduced delinquent behavior in adolescence correspond—to those of the longitudinal study of the Perry Preschool Project (Berrueta-Clement, Schweinhart, Barnett, Epstein and Weikart, 1984). Significant findings in other areas emerged from our follow-up study as well:

- Girls in the program group, but not boys, were performing significantly better in school than their counterparts in the control group. Interestingly, these positive findings only began to appear during early adolescence; information on the elementary school years indicated no differences between the program and control group. By the 7th and 8th grades, three-fourths of the program-group girls had C averages or better; none was failing and none had had more than 20 school absences during the previous year. In contrast, more than half the control group girls had averages below C; 16% were failing; and 31% had had more than 20 absences. Teachers rated girls from the program group as having more positive attitudes toward themselves and other people.
- Compared to control-group parents, parents who had been in the program reported feeling proud about the positive social attitudes and behaviors of their children and the degree of unity in their family. They were also more likely to advise young people to learn something about themselves and accomplish all they could, while control parents were more inclined to counsel young people to concentrate just on "getting by."
- Compared to control-group children, those in the program group felt more positively about themselves in early adolescence and were more likely to expect education to be a continuing part of their lives. Fifty-three percent of the program group but only 28% of the controls anticipated that they would be in school at age 17 or 18.

Statistically significant findings such as these are precious to practitioners, program developers, researchers, policymakers, and advocates concerned with the well-being and development of children and families. They bolster our clinical knowledge of the positive effects of high quality early childhood experience. Findings concerning the differences between program and control children that seem to emerge only over the long term, in important domains such as school performance and delinquency, are particularly important to bring to the attention of decisionmakers. In addition to being able to "chalk one up" on the side of the scorecard that says, "early intervention works," it is also important to describe in some detail what *kind* of early intervention seems to be effective, and for whom. Planners and implementers of demonstration programs must make clear whom they served, what they hoped to accomplish, how they proceeded, and the conceptual underpinnings of their interventions if others are to be able to understand and replicate their work. This article first gives a feeling for the philosophy and way of working of the Family Development Research Program, and second delineates the follow-up effort, procedural issues in this kind of research, and the meaning of its major findings.

The Family Development Research Program: Target audience and conceptual framework

Like other intervention programs begun in the 1960's and '70's, the Family Development Research Program (FDRP) attempted to break the well-documented link between low-education, low-income households and children's later educational difficulties. Unlike other programs which focused on preschoolers *or* on infants, *or* on parents, the FDRP provided a full complement of education, nutritional, health and safety, and human

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services resources to families beginning prenatally until children reached elementary school age (Honig, 1977; Honig and Lally, 1982; Lally and Honig, 1977a). In 1969, 1970, and 1971 FDRP recruited 108 families with incomes of less than $5000 per year (in 1970 dollars) into the program in the last trimester of pregnancy. Mothers had less than a high school education, and a history of either no paid work or semiskilled work. Their mean age was 18 years; more than 85% were single parent heads of households. Despite energetic attempts to maintain racial balance in the program, the majority of families served were black.

Our intervention was designed to influence the permanent environment of the child, the family and the home. We saw parents as the primary teachers and sustaining caregivers in a young child's life, and hoped to support parent strategies which would enhance the development of the child long after intervention ceased. Consequently, we viewed parent contact as the primary intervention and child care as supplementary; this strategy differed from that of child-oriented programs of the time, which saw enriched child care as the core of the program and parent contact as "outreach." In actual operation of the program, however, both parent contact and child care became crucially important and integrated aspects of the comprehensive, long-term intervention. We assumed that a guarantee of high quality child care for 50 weeks a year for the first five years of their children's lives would greatly assist families in meeting the life challenges they faced, as well as positively influence the perceptions, emotions, and intellect of the children served.

Five theoretical rationales shaped the goals and objectives of the intervention program.

- Piagetian equilibration theory, which stresses judicious provision of toys, materials, and human interactions in sensitive relationship to the developing abilities and understandings of the child, helped to shape the infant curriculum both in the home and center. Piaget's attention to the crucial importance of *active* child participation in the construction of knowledge was also emphasized.
- Language developmental theories suggested that adult modeling and expansion of child language, contingent responsiveness to early infant coos and babbles, interactive turn-taking talk, and frequent book reading would increase child language repertoire (Bernstein, 1964).
- Erikson's theory of each child developmental stage as, optimally, the positive outcome of a series of nuclear conflicts or struggles between opposing emotional adjustments and attunements, focused program concern on the development of basic trust, sturdy autonomy, and learning initiatives in the children served (Erikson, 1950).
- Saul Alinsky's (1971) theory of community organization shaped the way in which FDRP personnel

perceived their role in the community served and the tone with which parent contacts were maintained. Alinsky had theorized that "To give people help while denying them a significant part in the action contributes nothing to the development of the individual. In the deepest sense it is not giving but taking—taking their identity" (p. 123).

- From John Dewey and the British Infant School movement, the FDRP project drew the concepts of the importance of freedom of choice for children, encouragement of creativity, and design of an environment that supports exploration in a spatial rather than exclusively time-bounded organization of programmatic offerings.

Child care staff at the Syracuse University Children's Center functioned under a more specific set of agreed-upon assumptions. They believed that the program children were capable of:

1) learning something about anything in which they showed interest;

2) learning to understand that their actions and choices had an impact on others;

3) learning that cooperation and concern for the rights of others would ultimately allow them to express their own creativity, excitement, curiosity, and individuality more fully;

4) learning that wonder and exploration were encouraged by adults; and

5) imitating the actions of staff toward children and other adults.

Additionally, these children were treated as special creations, each with particular skills and specialties that would be appreciated by and useful to the larger society. These special powers were to be protected and allowed to rise to ascendance by the adults who spent the daytime hours with them. In summary, the context that was fostered set a daily tone of freedom of choice and awareness of responsibility; an expectation of success in each child; confidence in the fairness and consistency of the environment; an emphasis on creativity, excitement, and exploration in learning; expectation of internal rather than external motivation; and a safe, cheerful place to spend each day.

Program components

Parent involvement: The major thrust of FDRP was to maximize family functioning by supporting a rich quality of family interaction and increasing family cohesiveness. A cadre of paraprofessional home visitors called Child Development Trainers (CDTs) was recruited and trained intensively to encourage strong, nurturing mother-child relationships that involved giving affectionate bodily contact, respecting children's needs, and responding positively to young children's efforts to learn.

During weekly home visits, CDTs taught families Piagetian sensorimotor games during daily routines. They also helped mothers to learn ways to modify games and activities in order to match the unique interests and characteristics of the individual child. CDTs offered positive support and encouragement to mothers as they interacted with their children and also responded positively and actively to the parent's need to fulfill her aspirations for herself. Many mothers came to rely on the CDT as an advisor and confidante on personal relations, finances, career changes, and education. The CDT served as a liaison between the family and community support servides, including the child care component of FDRP; in addition, she helped families to learn to find and use neighborhood resources on their own, for example, giving families specific practice in learning how to make and maintain contact with school personnel as children reached school age.

The Parent Organization: As FDRP progressed, parents developed both formal and informal associations. One group of families, specifically concerned about the education of their children after FDRP, asked for training in classrooom observation and for information about parents' rights in relation to the schools. They observed Syracuse kindergarten and first grade classrooms and made their findings available to program parents so that they could be advocates for their children. Informally, parents joined together for cooperative food purchasing; two single mothers in the program moved in together to share resources.

The Children's Center: A pioneer child care and educational facility for infants, toddlers, and preschoolers, the Children's Center was founded in 1964 by Bettye Caldwell. When J. Ronald Lally became project director of FDRP in 1969, the Children's Center already had a well-trained staff and a strong local and national reputation. Lally added the FDRP home visitation component and an open-education model for children from 18 to 60 months of age. Alice Honig remained program director of the Center, where she supervised staff training and assessment of the multiple components of the FDRP.

The Children's Center, lodged in a huge church basement, included three main groupings that were designed to accommodate developmental stages of the children served.

Infants 6 to 15 months of age were cared for in an "Infant-Fold" five days a week for a half day each day. Each caregiver was assigned to four infants. Caregivers worked in pairs, with group size limited to eight infants. The caregiver assigned to an infant was expected to form the principal relationship with the child. Activities were tailored to the individual level of skill of each child. All caregivers were encouraged to use creativity in finding ways to embed Piagetian sensorimotor games, fine and gross motor activities, sensory stimulation and activities, and language and book experiences in daily activities, daily care routines and informal encounters, as well as in more formal learning experiences.

Babies from 15 to 18 months were in a special transition group with full-day care five days a week. Self-feeding was encouraged, and larger play spaces with sliding cabinets encouraged toddler autonomy and freer choice of materials. Comforting and emotional support from the caregivers remained freely available to these older babies.

Children from 18 to 60 months were together daily in a family style environment designed by Margaret Lay (Lay and Dopyera, 1977) and similar to the British Infant School in philosophy and structure. Children had freedom of choice and access to four major areas: large muscle, small muscle, sense perceptions, and creative expression/snack. Additionally, the children had a large variety of wheeled toys and equipment in the big gymnasium that was used in inclement weather when the children could not go outdoors to their enclosed play area. Children ate lunch in groups with a teacher at each table; parents were free to join the lunch groups and visit whenever they chose.

The family style program had several rules. No physical aggression was permitted. Materials had to stay in their appropriate areas and to be cared for, not destroyed. Thirty-second "time outs" were used for flagrant transgressions. The opportunity to interact with children of different ages was used by teachers to promote prosocial behavior and sensitive awareness among children of the differences between younger and older capabilities.

Staff training: Enhancing staff skills was as integral a part of FDRP as helping the children to flourish. *All* staff, including caregivers, home visitors, researchers, testers, secretarial staff, the cook, bus drivers, and driver aides, participated in intensive two-week training sessions every fall. These sessions were important for personal revival and renewal of motivation as well as for refining child observation skills and deepening understanding of Piaget and Erikson. During the year, staff held weekly case conferences to discuss in depth the progress, problems and strenghts of a particular child. Every staff member who could contribute to a child's experiences at the Center was invited to participate in these conferences, and frequently several staff members collaborated in devising ways to help a particular child.

Assessing the Family Development Research Program

The carefully spelled out goals of the FDRP program and the even more specifically defined roles and activities required of staff members made the tasks of assessment clear, if complex. A variety of psychometric tests and ecological observation measures in classrooms were administered to assess how the children were faring (see Lally and Honig, 1977a and 1977b for full details of all assessments). Parents were interviewed in depth after three and five years in the program to assess the effectiveness of the CDT's efforts. Weekly and Monthly Home Visit Reports permitted data gathering on the course of parental responsiveness to the CDT's work.

When program children were 36 months of age, a longitudinal control group was established for the duration of the FDRP. The control children were carefully matched in pairs with program children with respect to sex, ethnicity, birth ordinality, age, family income, family marital status, maternal age, and maternal education status (no high-school diploma) at time of the infant's birth. Stanford-Binet IQ scores, and many other tests and observational measures of program and matched control children, were compared at 36, 48, and 60 months. Scores for the program and controls were also collected at 72 months.

Short-term impact on child functioning

Cognitive functioning: At 36 months of age, program children scored significantly higher on the Binet test than their control counterparts (Lally and Honig, 1977b). As the children grew older, however, these differences disappeared. When they were 60 months of age (at the end of the program), program and control children looked similar to each other across a variety of measures of cognitive development and intellectual ability.

Social-emotional functioning: At 36 months of age, program children exhibited social-emotional functioning superior to that of control children as measured by the Social Emotional Observer Rating of Children (Emmerich, 1971). This superior functioning continued in kindergarten. In the first grade, program children continued to behave positively toward other children, but their behavior toward teachers had changed. Program children displayed both significantly more positive and negative behavior toward adults than control children did. Program children sought out teachers through many more negative bids than when in preschool or kindergarten and were observed to smile and laugh less frequently. In a complete report of this investigation, it was hypothesized by the researchers that the expectations of the children for personalized attention from the teacher were violated, and their behavior changed accordingly (Honig, Lally & Mathieson, 1982). A number of parents reported that their children were frustrated with their school experiences, with one parent reporting that her child complained that he wasn't learning anything.

Methodology of the ten-year follow-up study

In our comprehensive follow-up study, we sought to gather information on the functioning of the study children in school, in their family, and in the community. We also wanted to investigate how the family functioned as a unit and how it related to the community. Data were gathered from school records, court records and probation department records. We asked teachers to complete a questionnaire that involved rating the academic and social functioning of each study child in their class. Interviews of 2 to 2½ hours in length were conducted with the study children and one of their parents or guardians, almost all with the study child's mother. Parents completed a demographic data form, filled out questionnaires, and responded to open-ended questions on their perceptions of their child's school and social functioning, the quality of their family life, their aspirations, and the like. The study children completed a questionnaire and responded to various interview questions about their functioning in school, their social attitudes and behavior, their family life, and their aspirations. The interviewers were advanced students in one of the helping professions who were kept blind to family status in the study (program or control).

Of the 108 children who started the program, 82 completed the full five year intervention. Seventy-four of the matched controls remained in the sample through 60 months of age as well. Nine years later, when the longitudinal study commenced, we were able to obtain informed consent from 65 program families, representing 79% of the families who finished the program, and 54 control families, or 73% of the control families who were still in the sample at 60 months of age.

We found about 80% of the program and control families by publishing announcements in local newspapers, by distributing information about the study in local schools, and through word of mouth among study families and friends. Finding the last 20% of the follow-up sample was much more difficult. We hired a recruiter who had vast experience doing community work in low-income neighborhoods. He located families through informal conversation on the street and, ultimately, through developing a network of contacts in the neighborhoods where study families lived. It is noteworthy that this group of "hard-to-find" families, who were eventually found and who consented to participate, consisted of by and large the least organized and least stable families in the entire sample.

Contact with the families was made by the research team first to obtain signed permission forms and then later to schedule and conduct parent and child interviews. Maintaining contact with the families turned out to be difficult in a substantial number of cases. A subgroup of families within the sample moved frequently, often without leaving a forwarding address. Some lost telephone service, some would fail to be home at an appointed time for an interview, or, in a few cases, because of severe problems in the family such as domestic violence, some avoided having continued contact with the research team. As it turned out, parent interviews were conducted with 51 of the 65 follow-up program families and 42 of the 54 follow-up control families. For the child interview it was possible to perform 49 out of 65 possible program sample interviews and 39 out of 54 possible control sample interviews.

What the above data indicate is that it was impossible to maintain contact and conduct interviews with about 25% of both the follow-up program and control families from whom we were able to obtain parental consent. This is only part of the story, however. Among those families we were ultimately able to interview, it was much easier to maintain contact with and arrange interviews with the program families than with the control families. The last 10 interviews (about 25%) conducted with control families required an enormous amount of patience and persistence. Interviewers would arrive at a home at an appointed time only to find no one there. Because about half of these families had no telephone, someone from the research team would have to keep appearing until the family was at home. Unlike the families with whom it was easy to maintain contact and conduct interviews, the "hard to study" families were very impoverished and disorganized. The larger proportion of the "hard to study" families in the control follow-up sample, 25% of the control group interviewed versus 10% of the program group interviewed, was one indication that a substantial sub-group of families within the control group was functioning poorly.

In an analysis of the possible effects of attrition on the make-up of the follow-up program and control samples, we undertook two statistical comparisons. When we compared the follow-up program sample with the original program sample at the close of the intervention across five key variables (e.g., Stanford-Binet scores, mother's education) we found no significant differences. Likewise, the follow-up control sample did not differ significantly from the original control sample across the five variables.

Discussion of follow-up findings

As highlighted in the opening paragraphs of this report, the Syracuse Family Development Research Program clearly had a positive impact on the children and families who participated in the intervention. Thus far, the strongest program effects have been in the domain of social deviance and functioning in the community. The findings reported in this study correspond to other research that has shown high quality early childhood programs lower the incidence and severity of juvenile delinquency in children from low-income communities (Berrueta-Clement et al., 1984). The Syracuse children are still young. To the extent that early delinquent behavior predicts later criminality, we would expect the gap between the program and control group to increase. It is conceivable that the costs of criminal involvement in the control group, as compared to that in the program, will continue to mount.

In addition to the findings on juvenile delinquency, family interview data indicated that program families tended to value prosocial attitudes and behavior, education, and family unity. Likewise, program children tended to express more positive feelings about themselves, take a more active approach to personal problems, and see schooling as a vital part of their life. Thus, the program appeared not only to prevent severely deviant behavior, but also to be associated with more positive attitudes and values in the children and parents. The message that came across in the interview from the program families was a proactive approach to life or a belief that one can act to better one's circumstances, that one can take steps to reach one's full potential. This stood in contrast to the control families, who tended to emphasize that one should seek to survive or get by.

In the domain of school functioning, the program girls but not boys benefited from the Syracuse intervention. Multiple sources of data support this conclusion, including school grade average data, school attendance data, and teacher ratings.

It is important to recall that the transition to elementary school was difficult for both program boys and girls. No sex differences were found in the analysis of social/emotional functioning of program children in first grade. In both the program and control samples, girls were retained less often than boys during the elementary school years. However, only program girls showed improvements in school functioning as they entered junior high school.

Why did we find improvements in school only for the program girls? It may be that for a number of reasons the school years are more difficult for the black male child (Stevens, 1982). Perhaps the impact of the intervention was not strong enough for the program boys to counteract an elementary school experience that routinely involved restrictions, conflict and failure. This suggests that, to be optimally effective, intervention programs need to continue in some form throughout childhood, at the very least to support the positive effects of early intervention in a child's life.

One finding uncovered while doing this follow-up study must be addressed. We encountered what we believe to be a perplexing issue in doing longitudinal research with low-income, "multi-risk" families. Both the "hard to find" and "hard to study" families were families whose long-range outcomes tended to be negative. This may have led to a positive bias in the follow-up data for both the Syracuse program and control follow-up samples, though this positive bias was much more pronounced in the control sample. As it was, in investigating the incidence and severity of juvenile delinquency, we found many more control children in serious trouble. Of the last 10 control families interviewed, each interview having required a tremendous effort to complete, 6 of the families had a study child involved in juvenile delinquency. Thus, in order to obtain results that are as accurate as possible, an investment must be made to find and study those very families who are most difficult to find and study. Moreover, appropriate measures of difficulty in retrieving and investigating a follow-up sample need to be developed. With such measures, it will be possible to gauge more precisely the degree and type of attrition in longitudinal follow-up samples and how such attrition affects the interpretation of comparisons between program and control follow-up samples.

Finally, it is important to discuss, in general terms, just what worked, what did not, and what we would recommend for future longitudinal interventions with similar populations. Although it is almost impossible to separate out the specific effects of parent participation from the child's participation in the Children's Center, it seems clear that our original notion to involve families intimately as intervention agents paid off. The advice that program parents gave their children about how to function in life and the things program parents report they take pride in with regard to their parenting as compared with control parents seem key to the prosocial, motivational, and educational differences between program and control children. One hypothesis that could be generated for the long-range differences between the samples is the lasting impact on the parents and the parent-child relationship after intervention ceased.

One discouraging finding was that the intervention had practically no impact on family income and career advancement of the parents. It became painfully clear as follow-up data were being collected that many families, both program and control, still lived in poverty and in neighborhoods that they considered dangerous and harmful to the development of their children. A number of children interviewed discussed the discrepant goals of school and neighborhood and the difficulty they had integrating the two. We had hypothesized at the start of the intervention that the environment in which the child was raised would have a continuing effect on the child well after intervention ceased and that is why parent participation was so strongly emphasized. What was not emphasized strongly enough was the power of the neighborhood and the need for special supports during the transition from program to school.

The Family Development Research Program was successful in many ways, as our data suggest, with both the program boys and girls served. We feel that three modifications of the program would make similar undertakings even more effective. First, developmental transitions, such as the transition from preschool to school, should be carefully planned for. Abrupt endings to intervention should be avoided. Second, service institutions and agencies that are already a part of the community, including informal neighborhood organizations, should be intimately involved in the creation and continuation of an intervention. Third, programs should be designed so that they can change and adapt services based on continued readings of the changing family needs.

Bibliography

Alinsky, S.D. (1971). *Rules for radicals.* New York: Random House.

Bernstein, B. (1964). Social class, speech systems and psycho-therapy. In F. Riesman, J. Cohen & A. Pearl (Eds.), *Mental health of the poor* New York: Free Press of Glencoe.

Berrueta-Clement, J.R., Schweinhart, L.J., Barnett, W.S., Epstein, A.E. & Weikart, D.P. (1984). *Changed lives: The effects of the Perry Preschool Program on youths through age 19.* Ypsilanti, MI: High/Scope Press.

Emmerich, W. (1971). *Disadvantaged children and their first school experiences. Structure and development of personal-social behaviors in preschool settings.* (Report prepared for Project Head Start, Office of Child Development.) Princeton, NJ: Educational Testing Service.

Erikson, E. (1950). *Childhood and society.* New York: W.W. Norton.

Gray, S.W. (1983). Enduring effects of early intervention: Perspectives and perplexities. *Peabody Journal of Education, 60* (3), 70-84.

Gray, S.W., Ramsey, B.K. & Klaus, R.A. (1982). *From 3 to 20: The Early Training Project.* Baltimore: University Park Press.

Guttman, L. (1980). Recent structural laws of human behavior. *The Bulletin of the Institute of Communications Research,* Keio University, *14,* 1-12.

Hans, S. (1987). *Syracuse University longitudinal follow-up study: Current teachers' ratings of subjects' behaviors, attitudes and achievement.* Paper presented at the Society for Research in Child Development's biennial meeting, Baltimore.

Honig, A.S., Lally, J.R., and Mathieson (1982).

Lally, J.R. & Honig, A.S. (1977a). The Family Development Research Program: A program for prenatal infant and early chidlhood enrichment. In M.C. Day & R.D. Parker (Eds.) *The preschool in action: Exploring early childhood programs* (pp. 147-94). Boston: Allyn & Bacon.

Lally, J.R. & Honig, A.S. (1977b). *The Family Development Research Program: A program for prenatal, infant & early childhood enrichment. Final Report.* Syracuse, NY: Syracuse University.

Lay, M.Z. & Dopyera, J.E. (1977). *Becoming a teacher of young children.* Lexington, MA: D.C. Heath and Company.

Lazar, I. & Darlington, R. (1982). Lasting effects of early education: A report from the Consortium for Longitudinal Studies. *Monographs of the Society for Research in Child Development, 45,* (203, Serial No. 195).

Seitz, V., Rosenbaum, L.K., & Apfel, N.H. (1985). Effects of family support intervention: A ten-year follow-up. *Child Development, 56,* 376-391.

Stevens, J.H. (1982). Research in review: *From 3 to 20: The Early Training Project. Young Children, 37* (6), 57-64.

Perspectives on Practice

Promoting and Strengthening Family Functioning and Maternal Competencies: A Case Study

by
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Effective helping enables and empowers people to become better able to manage life events in a positive, growth producing manner (Dunst, 1987). The example of help giving described in this article was guided by a family-level assessment and intervention model that emphasized identification of family needs and strengths, mobilization of intrafamily and extrafamily resources for meeting needs, and use of enabling and empowering help giver roles (Dunst, Trivette, & Deal, 1988; Trivette, Deal, & Dunst, 1986).

The material presented in this case example was taken from records accumulated as part of help giver interactions that emphasized supporting a mother's sense of competence as a parent. The case study illustrates several of the steps that were taken in order to promote acquisition of parental competencies as a particular set of intrapersonal strengths (resources). The help giver-family exchanges described as part of this case study took place within the context of weekly home visits in the family's home. In this case the help giver was an early childhood teacher, who was able to consult as needed with a team including a pediatrician, a social worker, a psychologist, a speech-language pathologist, and a physical therapist. The help giver created a partnership that permitted the mother and the help giver to pool resources in order to meet family identified needs.

Case study

The "Day" family includes George (39 years of age), Shirley (21 years of age), their 7 month old daughter, Cindy, and David (14 years of age), George's son from a previous marriage. The "Days" also have a three year old son, Brian, who is in the custody of Shirley's mother, who lives in another state. George and Shirley were not married at the time of their son's birth and reluctantly gave up custody of their son under pressure from a number of professionals who felt the home was "not adequate for raising a child." The Day's are referred to as a "multi-problem" family by local agencies, and are under "close watch" in terms of protective supervision in the case of their daughter, Cindy.

At the time of our program involvement, the Days lived in a five room mobile home located in a mobile home park. George graduated from high school and was employed as an assembly worker in a local furniture factory. Shirley, who remained at home to care for Cindy, completed the tenth grade in a special education class. She shared with the help giver that she was labeled mentally retarded in the seventh grade. She also described herself as having "nerve problems," and at various times had been under the care of a psychiatrist who prescribed medication for her nerves. Shirley also shared that she has had aspirations of getting her high school equivalency diploma, and talked of wanting to work, perhaps in a sheltered workshop.

The Day family was referred to our program by a county homemaker service provider with the local department of social services. The family has received homemaker services weekly and Shirley has attended parenting classes, also offered by the same agency, once weekly. The social services worker made the referral based on concerns of a number of professionals with whom the family had contact because they felt Cindy was developing slowly.

During the initial contact with the family, both George and Shirley indicated that their number one priority was "keeping their family together," especially in light of the fact that they were "forced" into giving up the custody of their son, Brian. The Day family has had a long history of involvement with a variety of professionals from different human service agencies, few of which they spoke of in positive terms. Indeed, it was not surprising to find the Days reluctant to allow the help giver from our program to enter their home. Their decision to allow the help giver to visit the family as well as their "acceptance" of subsequent services seemed to be based more on their fear of negative consequences rather than a perceived need or desire for help.

Initially it was important that the family see that our program emphasizes supporting and strengthening families in a way that is responsive to family identified needs. A considerable amount of time was at first spent assuring and reassuring George and Shirley that the help giver would be available to help with things that the family felt were important. Establishing rapport and trust were major emphases of this early relationship building between the family and help giver.

Over the course of several home visits, considerable time was devoted to identifying family needs. Even though the Days were able to repeat the concerns of

Enabling and Empowering Families: Principles and Guidelines for Practice by Carl J. Dunst, Carol M. Trivette, and Angela G. Deal is published by Brookline Books, P.O. Box 1046, Cambridge, MA 02238 (Cost: $22.95). The authors describe a needs-based assessment and intervention strategy that has evolved from seven years of clinical and research experience with developmentally at-risk preschoolers and their families. The methods and strategies described in the book are designed to promote their social support networks in a way that enhances a sense of intrapersonal self-efficacy.

other professionals, such as "slow motor development" in reference to Cindy's behavior, these terms did not seem to hold much meaning for the family. In our contacts with Shirley and George, identifying family needs was accomplished by having them describe things they did with Cindy during daily family routines such as dressing and feeding Cindy, entertaining her, and so on. It was within the context of describing how Cindy was cared for that Shirley began to express her frustrations about Cindy being a colicky baby who cried frequently and "got on her nerves." (To the help giver, Cindy appeared pleasant, friendly and smiling, not a difficult baby by ordinary standards. Her mother, however, seemed overwhelmed by multiple demands.) When asked how she dealt with Cindy when she became upset, Shirley said she "put the baby in her crib and gave her a bottle to keep her quiet." As a consequence, the baby was somewhat overweight for her age and was spending a great deal of time in her crib. Further discussion with the family revealed that because Cindy "got on Shirley's nerves," she often became so upset that she could not get around to doing other household chores.

The content of the discussion with both George and Shirley included numerous negative comments directed both at themselves and each other. The help giver attempted to restate and reframe these negative comments in a more positive way to point out the family's strengths and capabilities. Negative comments directed toward one another, for example, were restated in a way that emphasized interest in the well-being of the family (e.g., "George, I can tell it bothers you when Shirley gets upset with Cindy. This shows how concerned you are about your daughter's happiness."). Similarly, Shirley's negative statements about herself were also reframed to point out the "good things she was doing" (e.g., "Shirley, although your sense of frustration is upsetting to you, I can't help but notice how happy Cindy is since you've been playing with her.").

A number of specific needs were identified by having the Days "talk through" their daily family routine. These included (1) Cindy's ability to play independently and entertain herself so that Shirley could get her household chores done, (2) the need for Shirley and George to have time to spend together, (3) Shirley becoming better able to "keep Cindy from crying and keep her happy," and (4) Cindy losing weight (the mother attributed Cindy's lack of crawling and pulling-to-stand to being "too fat to get around").

Mobilizing resources to meet these needs was accomplished in a number of ways. First, major emphasis was placed on supporting the things Shirley already did well as a way of building her self-confidence as a mother. This was done by asking her to talk about the times of day that Cindy was the happiest, and to think about what she did to keep Cindy contented. Shirley was able to show the help giver the things she did with Cindy to get her to play with toys, and the help giver suggested ways to use "little tricks" to get Cindy to do other things like rolling over or turning around while on her stomach. The help giver also demonstrated for Shirley how she could encourage Cindy's independence in play by placing Cindy on a blanket on the floor with a number of toys in front of her. Shirley quickly realized that the baby was content on the blanket with the toys for short periods of time which gave her opportunities to do the chores she needed to get done. Shirley was pleased with herself in bringing about these small changes in her daily life. The help giver also took pictures of Shirley playing and interacting wtih Cindy which Shirley displayed around the house. This helped Shirley feel proud and more competent, and illustrated for other family members the positive aspects of parent-child interactions between Shirley and Cindy.

In addressing each child-related need, the help giver was deliberate and careful to empower Shirley by sharing information or by modeling techniques that led to Shirley's success in meeting goals. Consequently, while addressing Cindy's needs, Shirley became more confident as a parent, which in turn helped her fulfill one of her desired primary roles in her family.

For example, Shirley described dinnertime as a hectic time, and talked about having to find a way of keeping Cindy occupied so she could cook and set the table. After some discussion about Shirley's concerns, it was discovered that Cindy became fussy and upset about an hour before dinner time because "she gets hungry and doesn't like to wait until her daddy gets home to eat." The help giver suggested that maybe Shirley could feed Cindy dinner earlier, and while Cindy was eating, Shirley could have time to fix dinner for the rest of the family. Shirley liked the idea and found that this arrangement helped to reduce the stress associated with dinnertime.

Another need identified by Shirley and George was spending more time together. Identifying a baby-sitter for Cindy so that Shirley and George could spend time together proved to be relatively easy. When asked if there were any relatives, friends, or neighbors who might baby-sit for Cindy, Shirley talked about Sharon, George's daughter from a previous marriage, with whom Shirley often socialized. Shirley said she sometimes watched Sharon's two children; Sharon in return would help out in small emergencies as well as help with chores like cleaning the house. When asked if Shirley thought Sharon would be willing to watch Cindy one night a week for two or three hours so she and George could go out, Shirley thought she would and decided to ask Sharon about "exchanging baby-sitting services."

When Shirley brought up her concern about Cindy's weight, the help giver took this as an opportunity to promote more interactions with other professionals. When Shirley asked the help giver if she had any information that might help her change Cindy's diet, the help giver said she was not very knowledgeable in this area, but that she remembered Shirley telling her about the public health nurse who had visited the family. Together, the help giver and Shirley made plans for Shirley to make an appointment to visit the nurse. The help giver and Shirley were able to talk through how Shirley would make an appointment with the health department nurse, how she would make arrangements for transportation with one of George's children to get to the appointment, and what she would say when she talked with the nurse. As a result of this interaction, the help giver was able to set the occasion for Shirley to have a successful experience with

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asking for help from a community agency. Prior to this experience the Day's viewed professional help givers as intruding in their lives, and always focusing on what was wrong with their family. Not surprisingly, they found many of these interactions not to be helpful. Shirley's experience with the public health nurse was the beginning of many more interactions to come where Shirley expressed what she wanted from help givers rather than waiting for them to tell her what she would be doing.

As her abilities to interact with Cindy and to manage other day-to-day needs improved, Shirley's self-confidence grew. Shirley enjoyed Cindy more as the little girl became able to do more things, to walk independently, instead of needing to be carried, and to respond more readily to her mother. Shirley also came to understand that Cindy did not cry because she "did not like" her mother. Shirley's competence and sense of control also seemed to promote a better relationship between herself and George. She was pleased with the changes she had made, and George was more positive about Shirley's interactions with Cindy and about Cindy's development.

Just as things seemed to be going better for the family, especially in terms of Shirley's sense of competence as a parent, a report was made, possibly by neighbors, to the department of social services concerning child neglect. The family was devastated. The help giver recognized that there remained reason to be concerned about Shirley's capabilities as a mother but felt that the program's ongoing involvement provided adequate protection for Cindy. Both Shirley and George shared their feelings of anger about the report with the help giver and expressed their frustration about "not knowing what people expected from them." The Days were able to deal with the department of social services in a more constructive manner than previously: the time-limited "close supervision" instituted by the department included parenting classes, which Shirley enjoyed as opportunities to socialize, visits by a lay home visitor, and homemaker service once a week.

While "what do people expect?" contined as a theme in the help giver's contacts with the family, the focus of discussion shifted gradually to Cindy's development. A recent assessment found Cindy slightly slow in her motor skills but generally within normal limits. She will soon be entering Head Start.

Bibliography

Dunst, C.J. (1987). *What is effective helping?* Paper presented at the Fifth Biennial National Training Institute of the National Center for Clinical Infant Programs, Washington DC, December, 1987.

Dunst, C.J., & Trivette, C.M. (1987). Enabling and empowering families: Conceptual and intervention issues. *School Psychology Review, 16*, 443-456.

Dunst, C.J., Trivette, C.M., & Deal, A.G. (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books.

Trivette, C.M., Deal, A., & Dunst, C.J. (1986). Family needs, sources of support, and professional roles: Critical elements of family systems assessment and intervention. *Diagnostique, 11*, 246-267.

REGINALD S. LOURIE: 1908-1988

The National Center for Clinical Infant Programs mourns the loss on March 20, 1988 of Reginald S. Lourie, a founding member and first chairman of NCCIP. Reginald Lourie was a pediatrician, child psychiatrist, and psychoanalyst whose unique ability to mobilize a consensus of compassion created new opportunities for thousands of children and families in this country.

Reginald Lourie came to Washington, D.C. in 1948 to join the staff at Children's Hospital and became its director of psychiatry. He also served as medical director of Hillcrest Children's Center and the Regional Center for Infants and Young Children.

As a faculty member at the medical schools of George Washington, Howard, and Georgetown universities, he helped train hundreds of child psychiatrists. He also was influential in teaching young pediatricians to consider mental and emotional factors in their treatment of children.

Reg Lourie was concerned throughout his career with the prevention of mental and emotional disabilities. Understanding that sick children need to be with their parents as much as possible, he played a key role in liberalizing visiting hours for parents of hospitalized children. When he joined the staff of Children's Hospital, parents were allowed to visit their children only one or two hours a week, on the theory that their presence would be disruptive to doctors and nurses. Lourie had that changed to the present standard, which allows parents almost unlimited visiting privileges.

Reginald Lourie had an impact on national policy and programs for children. He served as chairman of President John F. Kennedy's Task Force on the Mental Health of Children and was on the national founding and planning committee for Head Start. Even as the Head Start program was being developed in 1964 for 4 and 5 year olds, Lourie and others pointed out that many children needed help in the earliest years of life. Several years later, Head Start's Parent/Child Centers were created to support the development of infants and their families.

Reg Lourie's attention to the importance of the first three years of life and the opportunities to enhance the healthy growth of very young children and their families through preventive approaches during this period has had a major impact on clinical practice and on public policy initiatives. Professionals from a wide range of disciplines are now involved in the field of infant mental health. Pioneering organizations and initiatives such as the National Center for Clinical Infant Programs, the Regional Center for Infants and Young Children, and the Center for Successful Child Development (the "Beethoven Project") reflect Dr. Lourie's vision. Legislation such as the Education for the Handicapped Act Amendments of 1986, the Parental and Medical Leave Act, and the Act for Better Child Care are in keeping with Reginald Lourie's talent for synthesizing complex developmental findings from several fields of scientific inquiry and interpreting these discoveries in a way that helps professionals and policymakers unite to improve the current and future lives of vulnerable young children.

Reg Lourie received numerous honors for his many contributions. In December, 1987 he was presented with the Dolley Madison Award of the National Center for Clinical Infant Programs. The text of that award described Lourie as "a colleague, teacher and friend (who) possessed the uncanny ability to see through posturing, indifference and even anger to the core human need for dependency and caring; who always sees in each person the adaptive struggle for closeness and intimacy and whose legendary anecdotes and stories sculpt truths into view, transforming unsmiling doubters into grinning believers."

Those of us in the National Center for Clinical Infant Programs and all across the country who have had the privilege of knowing, learning from, and leaning on Reg Lourie will continue to be inspired by his deep wisdom, his broad compassion, his boundless optimism, and his fierce commitment to all the children of this country.

Publications

The Health of America's Children: Maternal and Child Health Data Book—Dana Hughes, Kay Johnson, Sara Rosenbaum, Elizabeth Butler, and Janet Simons (Washington, D.C.: The Children's Defense Fund, 1988). Available from CDF, 122 C Street, N.W., Washington, DC 20001 for $12.95.

This 265-page report describes the current status of maternal and infant health in the United States; analyzes national, state, and large city infant mortality rates; compares U.S. infant mortality and low-birthweight rates with those of other countries; and assesses American women's access to prenatal care, patterns of childbearing among teenagers and unmarried women, and rates of progress toward maternal and infant health objectives set for 1990.

Key findings of the report include:

- The year 1985 was the first year since at least 1960 that overall neonatal mortality failed to decline in the United States.
- The percentage of babies born at low birthweight increased in 1985 for the first time in 20 years, and the prematurity rate increased by 4%.
- In 1985 nearly 25% of all infants were born to mothers who received late or no prenatal care.
- The overall U.S. infant mortality rate placed it 19th in the world, behind such countries as Spain and Singapore.
- Medicaid and the Special Supplemental Food Program for Women, Infants and Children (WIC) reach fewer than half of all women and children in poverty or eligible for WIC.

Healthy Children: Investing in the Future—U.S. Congress, Office of Technology Assessment (Washington, D.C.: U.S. Government Printing Office, February, 1988). Available as GPO Stock Number 052-003-01081-0 from Superintendent of Documents, Government Printing Office, Washington, DC 20402-9325 for $13.00.

This 300-page report summarizes recent trends in infant mortality and young children's health status and examines the costs and effectiveness of selected preventive strategies for improving children's health. It also examines problems in children's access to appropriate medical care.

The Office of Technology Assessment (OTA) found that extending Medicaid benefits to cover all pregnant women in poverty, assuring that Medicaid children actually receive well-child care visits sufficient to complete immunization, and encouraging states to enact tougher child safety restraint laws are all actions that would yield cost savings in the U.S. health care system. Strategies that would improve children's health but would also cost more would be for Congress to require Medicaid to pay children's physicians higher fees and for states to expand newborn screening programs to cover more diseases. Finally, two promising strategies are school based clinics for adolescents at high risk of unwanted pregnancy and nurse home visitor programs for pregnant women and children in families at high risk of child maltreatment.

Infancy to Adolescence: Opportunities for Success—Hearing before the Select Committee on Children, Youth and Families, House of Representatives, Washington, D.C., April 28, 1987. Available from the Select Committee, 385 House Office Building Annex 2, Washington, DC 20515.

The testimony presented before the Select Committee on Children, Youth and Families in this hearing was designed to expand committee members' knowledge of early intervention at several critical points during infancy, early childhood, and early and later adolescence. Of particular interest to *Zero to Three* readers may be the statements of David Hamburg, M.D., president of the Carnegie Corporation of New York; C. Arden Miller, M.D., professor and chairman, Department of Maternal and Child Health, School of Public Health, University of North Carolina at Chapel Hill; and James Garbarino, Ph.D., president, Erikson Institute for Advanced Study in Child Development. Hamburg stresses the importance of prenatal care, immunization, promotion of attachment and good parenting, early education, and prevention of injuries as interventions that have worked to prevent damage and promote healthy development in infancy and childhood. Miller's testimony summarizes the analysis of medical and social services to pregnant women, newborns, and their families in ten European countries that was published by NCCIP in July, 1987 as the report *Maternal Health and Infant Survival*. Garbarino focuses on preventing academic failure, improving the safety of the child's environment, and improving the quality of child care as "a basic component of a modern society."

America's Family Support Programs—Sharon Kagan, Douglas Powell, Bernice Weissbourd, editors (New Haven, CT: Yale University Press, 1987) $30.00.

The purpose of this volume is to examine the growth and collective impact of the diverse efforts that have come in the last decade to be known as "family support programs." Six sections of the book provide a conceptual framework; describe the historical context for family support approaches; illustrate types of family support programs, including programs for new families, day care and support for families of children with special needs; address program development and implementation, including issues of ethnicity as well as staffing and funding; discuss research and evaluation; and offer recommendations for the future.

The editors see the family support movement as moving from the stage of individual program development to the "development and financing of a field." They believe that the long-term success of family support is essential in revitalizing this country's human services, but emphasize that these programs must aid, not supplant, current federal efforts on behalf of children and families. They offer recommendations to broaden participation and training, to enhance public awareness, to expand advocacy efforts, to mobilize the research community, to expand the financial commit-

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ment of foundations, and to clarify the government role.

Contributors to the volume include Urie Bronfenbrenner, Donald Campbell, Marilee Comfort, Johanna Freedman, James Garbarino, Shirley Jenkins, Robert Moroney, Susan Muenchow, Peggy Pizzo, Victoria Seitz, Alexandra Shelley, Jack P. Shonkoff, Lois Pall Wandersman, Heather Weiss, Bernice Weissbourd, Ronald Wiegerink, and Kenton Williams.

The National State of Child Care Regulation, 1986—Gwen Morgan (Watertown, MA: Work/Family Directions, Inc., 1987) Available as Publication #725 from NAEYC, 1834 Connecticut Avenue, N.W., Washington, D.C. 20009 for $25.00.

This report compiles information on child care licensing systems of every state and the District of Columbia, including what programs are covered, what agency does the licensing and the method used, and the frequency of inspections. Certain key requirements have been selected to be highlighted, including staff qualifications, ratios and group size, discipline, the parents' role, developmental aspects of the program, immunization, other key health requirements, insurance, amount of physical space, and criminal records checks. The author and her colleagues at Work/Family Directions, a consulting firm that manages child care resource and referral services, not that child care regulations differ from state to state on almost every aspect of what is required. Morgan suggests that the lack of accessible comparative information has contributed to the diversity and its confusing effects; she also notes that states with weak regulations have been motivated to improve when they recognize their status in relationship to others.

Some of the highlights and trends in the report include:

- For infants, a child/staff ratio of 4:1 is the most common ratio. However, for toddlers as young as 18 months, only 28 states have ratios of 5:1 or lower.
- States have not responded to current knowledge on the importance of regulating group size in centers. Twenty-six states have no regulations concerning group size for infants and toddlers.
- Eleven states permit 5 or more babies in family day care without an assistant.
- Only 28 states require a source of fresh water in the infant changing room for centers.
- Forty-one states have updated their requirements for centers in the last 5 years, and most of the changes represent improvements in quality and more precise definitions for implementation—a trend toward lowering the child/staff ratio for infants is noteworthy.

Over a Barrel: Working Mothers Talk About Child Care—Caroline Zinsser (New York: Center for Public Advocacy Research, 1987). Available from the Center for Public Advocacy Research, 12 West 37th Street, New York, NY 10018 for $5.

The purpose of this study was to explore issues of how parents choose child care, what factors determine their choices, and how their work is related to their child care arrangements. Twenty-four working women participated in four discussion groups, talking freely in their own terms rather than responding to structured interviews or questionnaires. An analysis of transcribed audiotapes revealed a number of issues:

- Parents' choices of child care do not necessarily reflect their preferences. Women spoke repeatedly of the necessity of making the best of what was available, of being "over a barrel."
- Informal and unregulated care is often of poor quality, unreliable, and lacks continuity.
- Parents in the study tended to divide child care into "babysitting" and "day care." The study parents felt licensing was *not* important for the former but was assumed for established centers.
- Parents are more concerned with the capabilities of the caregiver than with other factors subject to licensing.
- Many child care arrangements are complicated and fragile, with no back-up arrangements.

Zinsser suggests a number of policy recommendations to address these and other concerns raised by the mothers in the study.

The Parental Leave Crisis: Toward a National Policy—Edward F. Zigler and Meryl Frank, editors (New Haven, Connecticut: Yale University Press, 1988) $30.00.

In 1983, the Bush Center in Child Development and Social Policy at Yale University conceived of a project to study the impact on families and children of the lack of leave time and support for parenting in the early months of an infant's life. During the course of two years, an advisory committee of leading scholars considered research on the well-being of infants and their families, the demographic features of the family and the work force, infant care preferences of parents, the status of infant day care, public and private infant care leave policies in the United States and abroad, and financing and implementation issues. In 1985, the Advisory Committee on Infant Care Leave recommended that infant care leaves should be available for a minimum of six months, with partial income replacement included for three months and benefit continuation and job protection available for the entire six-months leave period. Additional recommendations addressed financing of leave, other forms of employer assistance to families of infants, and the improvement of out-of-home infant care.

The chapters of this 350-page volume stress a relationship between two concerns: "that parents need time with their newborn infants to establish patterns of trust and integrate family relationships; and that the quality of day care infants receive contributes to their own development as well as to that of the total family system."

Contributors to the volume include Joseph Allen, Jay Belsky, T. Berry Brazelton, Urie Bronfenbrenner, Barbara Butler, Ellen Farber, Meryl Frank, Thomas Gamble, Sheila Kamerman, Thomas Kean, Susan Muenchow, Mary Piccirillo, Peggy Pizzo, Joseph Pleck, Patricia Schroeder, Kathryn Young, and Edward Zigler.

Clinical Implications of Attachment—Jay Belsky and Teresa Nezworski, editors (Hillsdale, New Jersey: Lawrence Erlbaum Associates, 1985) $49.95.

This volume is based on the work of a study group organized under the auspices of the Society for Research in Child Development to consider clinical implications of attachment. Invited to participate in the group were developmental psychologists and clinicians from several disciplines who not only were knowledgeable about attachment theory and research but who also had experience treating young children and their families. The group explored a variety of issues, including the predictive utility of Strange Situation assessments, the conditions under which insecurity of attachment is related to subsequent difficulties, the origins of individual differences in attachment security, and intervention strategies that might prove useful in ameliorating the developmental risks that appeared to be associated with insecure attachment relationships.

Contributors to the volume include John Bates, Kathryn Bayles, Jay Belsky, Cathryn Booth, Jude Cassidy, Patricia Crittenden, Mark Greenberg, Stanley Greenspan, Russell Isabella, R. Rogers Kobak, Alicia Lieberman, Susan Lollis, Teresa Nezworski, Jeree Pawl, Kenneth Rubin, Matthew Speltz, Susan J. Speeker, L. Alan Sroufe, and William J. Tolan.

The Origins of Morality in Early Childhood—Carol Gilligan (Working Paper Series, No. 7, The Project on Interdependence at Racliffe College). Available from the Project on Interdependence, Fay House, Radcliffe College, 10 Garden Street, Cambridge, MA 02138 for $4.00.

Drawing on recent research in infancy by Kagan, Stern, and others, Carol Gilligan locates the origins of morality in the young child's awareness of self in relation to others. She identifies two dimensions of early childhood relationships that shape this awareness in different ways.

- The dimension of *inequality*, reflected in the child's awareness of being smaller and less capable than adults and older children, has been stressed by theorists who have defined morality as justice and have aligned development with the child's progress toward a position of equality and independence.
- The experience of *attachment* creates a very different awareness of self—as capable of having an effect on others, as able to move others and to be moved by them. Gilligan suggests that the moral implications of attachment relationships have generally been overlooked in theories of moral development, partly because the passivity of early childhood love has been stressed rather than the child's activity in creating and sustaining connections with others. In Gilligan's view, the experience of attachment generates a perspective on relationships that underlies the conception of morality as love.

Preventing Mental Disorders: A Research Perspective—Jane Steinberg and Morton Silverman, editors (Rockville, Maryland: Department of Health and Human Services, 1987). Available from NIMH, Office of Scientific Information, Public Inquiries Branch, 5600 Fishers Lane (Room 15C-05), Rockville, MD 20857 as DHHS Publication No. (ADM) 87-1492.

This 250-page monograph represents a retrospective of the efforts of the Center for Prevention Research from 1982 to 1986 to serve as a focal point within the National Institute of Mental Health for stimulating research directed at preventing mental illness and promoting mental health. Seventeen chapters address models of prevention, criteria for prevention research, refining risk factors, proceeding from risk factors to preventive trials, methodological considerations, and ethical dilemmas in prevention research.

Arnold Sameroff's essay on "Transactional Risk Factors and Prevention" reviews a transactional model of development that includes both the child and the child's experiences and that takes into account the importance of transitions in human development. Sameroff notes that developmental outcomes for young children are multiply determined, with no single risk factor always present or always absent in cases where high levels of socioemotional and intellectual incompetency are found. Since many risk factors are difficult or impossible to change, Sameroff suggests that intervention strategies to address variables of mental health, parental perspectives, and parent-child interaction patterns should be employed. Such strategies include "remediation" (changing the child), "redefinition" (identifying for parents the possibilities for normal childrearing within what appears to be a deviant situation), and "reeducation" (teaching parents how to raise children).

Preventing Maladjustment from Infancy through Adolescence—Annette Rickel and LaRue Allen (Newbury Park, California: Sage Publications, Inc., 1987) $12.95, paper.

This book, Volume 11 in the Developmental Clinical Psychology and Psychiatry Series, examines the theoretical and historical issues of prevention with children, looking at developmental risk for infants from the point of view of a continuum of "reproductive causality" and a continuum of "caretaking causality."

The authors emphasize the importance of incorporating parental involvement in the design of prevention efforts. They suggest that the most effective intervention, in terms of both immediate and long-range positive change, has been associated with a continuing, active involvement of parents in the process. Parental participation not only benefits the child directly and improved the parent-child relationship, but also increases the parent's own self-concept, autonomy, and feelings of competence. The last change may, the authors suggest, be responsible for the first two. The authors note that much of the literature supports the notion that intervention should focus on the parents of high-risk children, because enhancement of child performance follows naturally from positive changes effected in the caretaker.

Call for Papers

The **World Association of Infant Psychiatry and Allied Disciplines (WAIPAD)** invites submissions for symposia, poster papers, workshop seminars, case presentations, and a media theater, to be presented at the 4th World Congress on Infant Psychiatry and Allied Disciplines, to be held September 20-24, 1989, in Lugano, Switzerland. Subthemes for the Congress are New Directions in Psychobiology, New Directions for the Clinician, Cultural Variations and Infant Development, New Directions in Preventive Intervention and Treatment, and New Directions in Studies of Atypical Development. **All submissions must be received by August 1, 1988.** For information contact Hiram E. Fitzgerald, Department of Psychology, Michigan State University, East Lansing, MI 48824-1117.

The **Literature Prize Committee of the Margaret S. Mahler Psychiatric Research Foundation** will award a prize of $750 to the author of the best original paper dealing with clinical, theoretical, or research issues specifically related to Mahler's concepts of separation-individuation. **Six copies of papers must be received by December 31, 1988,** by Dr. Marjorie Harley, 201 St. Martins Road, Baltimore, MD 21218.

Conference Call

June, 1988

June 8: The *North Shore Child and Family Guidance Center* will hold its fourth annual conference in Garden City, New York, with the theme "Promoting Resilience in the Vulnerable Child." Arnold J. Sameroff and Frank Pressman will present special addresses. Write to Andrew Malekoff, 480 Old Westbury Road, Roslyn Heights, NY 11577.

June 10-11: *The Certificate Program in Infant Specialist Interdisciplinary Studies of Rutgers University* will sponsor a weekend institute in New Brunswick, New Jersey entitled "The Infant Mental Health Perspective in Services to At-Risk Infants and Their Families." Faculty will include Barbara Kalmanson, Steve Seligman, Lorraine McCune, Patricia Hill, and Wendy Matthews, who will address current issues in infant mental health, infant-parent approaches with at-risk families, and helping parents enhance cognitive and affective development through play. For information contact Lorraine McCune, Rutgers Graduate School of Education, 10 Seminary Place, New Brunswick, NJ 08903, tel: (201) 932-7812.

June 11-15: The *Association for the Care of Children's Health* will sponsor its 6th Annual Parent Network Meeting (June 11-12) and 23rd Annual ACCH Conference (June 12-15) in Cleveland, Ohio. The Parent Networking Meeting will feature a luncheon address by Kathleen Kirk Bishop. Lizbeth Vincent will speak to the conference on the topic "Parent-Educator-Health Professional: Partnerships for Care." Contact ACCH, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016, tel: (202) 244-1801.

June 13-July 22: *Children's Hospital Medical Center of Akron* and *Kent State University* will sponsor a Neurodevelopmental Treatment Certification Course for Teachers in Tallmadge, Ohio. Instructors will include Philippa Campbell and Catherine LaForme. Contact Joan Markowski, Family Child Learning Center, 90 W. Overdale Drive, Tallmadge, OH 44278, tel: (216) 633-2055.

June 13-17: The *Frank Porter Graham Child Development Center* will hold its Annual Intensive Summer Institute in Chapel Hill, North Carolina. Participants can choose in-depth study of infant/toddler curriculum and environment with Thelma Harms; mainstreaming in infant and preschool education with Don Bailey, or state policy issues for P.L. 99-457 with James Gallagher. Write or call Pam Rolandelli, FPG Summer Institute, CB #8040, Suite 300 NCNB Plaza, UNC-Chapel Hill, Chapel Hill, NC 27599-8040, tel: (919) 962-7360.

June 17-20: The *Bank Street College Infant and Parent Development Program* will hold an institute in New York City for caregivers of infants and toddlers, directors of 0-3 programs, and other practitioners. The conference will be limited to 45 participants. Faculty will include Bernice Weissbourd, Ellen Galinsky, Jan Drucker, Virginia Casper, Nancy Balaban and Emily Schrag. For applications write to Nancy Balaban, Director, Infant and Parent Development Program, Bank Street College, 610 West 112th Street, New York, NY 10025.

June 20-24: *Syracuse University* will hold its 12th Annual Quality Infant/Toddler Caregiving Workshop in Syracuse, New York. The workshop will be taught primarily by Alice Honig and will include observations and interactions with infants and parents. Write or call Dr. Connor Walters, Administrative Assistant, Syracuse University, 201 Slocum Hall, Syracuse, NY 13244-1250, tel (315) 423-2757.

June 20-24: *Erikson Institute* will offer advanced training in child abuse prevention in Chicago, Illinois. James Garbarino, Anne Cohn, Jon Conte, Judith Musick, and Bernice Weissbourd will address topics including the causes of child maltreatment, program evaluation, program development, parent education, sexual abuse, psychological maltreatment and social policy. Contact the Registrar, Erikson Institute, 25 West Chicago Avenue, Chicago, IL 60610, tel: (312) 280-7302.

June 20-24: The *C. Henry Kempe National Center for Prevention and Treatment of Child Abuse and Neglect* and the *Department of Pediatrics of the University of Colorado Health Sciences Center* will sponsor the 17th annual Child Abuse and Neglect Symposium in Keystone, Colorado. Plenary sessions will address origins of disturbed relationships, dilemmas in diagnosis and management of special cases; risk factors, victimization and outcomes; and community and systems approaches. The conference will also include 22 seminars and a meeting of the KEEPSAFE network, for professionals encountering preschool-aged abused children and their families. Contact the Kempe National Center, 1205 Oneida Street, Denver, CO 80220, tel: (303) 321-3963.

June 22-24: *Contemporary Forums* will hold a conference in Washington, D.C. entitled "The Fetus and Newborn: State of the Art Care." Contact Contemporary Forums, 530 LaGonda Way, Suite E, Danville, CA 94526, tel: (415) 820-2800.

July, 1988

July 11-15, August 1-5: *Child Development Resources* will hold its Third Annual Early Intervention Summer Institute in July in Denver, Colorado and in August in Williamsburg, Virginia. The theme will be "Integrating Service Delivery: Policy, Ethics and the IFSP." Write to Child Development Resources, Inc., P.O. Box 299, 6325 Centerville Rd., Lightfoot, VA 23090.

July 21-22: *Project SUNRISE* of the *Western Carolina Center* will present a national training institute at Hilton Head Island, South Carolina entitled "Training for Excellence: Strategies for the Future in Early Intervention." For information contact Renae Emrani, Project SUNRISE, Family, Infant and Preschool Program, Western Carolina Center, 300 Enola Road, Morganton, NC 28655, tel: (704) 433-2865.

July 28-30: The third biennial *NCAST Institute*, entitled "Players and Process: Bringing about Change in Organizations and Individuals," will be held in Seattle, Washington. Speakers addressing the theme of changing organizations will include Everett Rodgers, Anita Spietz, Margery Robison, Kathy Peppe, Connie Lybarger, and Charlene Snyder. Kathryn Barnard, Kristin Swanson-Kauffman, Claudia Spencer, Betty Sullivan, and Anita Spietz will discuss changing individuals. Cathryn Booth, Patricia Brandt, Anita Spietz, and Kathryn Barnard will describe assessment for change. Write or call NCAST, University of Washington, WJ-10, Seattle, WA 98195, tel: (206) 543-8528.

July 29-30: The San Diego Chapters of the *American Physical Therapy Association* and *Occupational Therapy Association of California* in cooperation with *Sensory Integration International* will sponsor the 16th Annual Sensorimotor Integration Symposium, entitled "Incorporating Manual Therapy Techniques with SI and NDT," in San Diego, California. Write to P.O. Box 33185, San Diego, CA 92103, c/o SENSORIMOTOR or call (619) 692-9115 for information.

August, 1988

August 3-6: The *National Association for Family Day Care* will hold its fourth bi-annual conference in San Mateo, California. London Smith will be the keynote speaker. For information write to NAFDC, 815 15th Street, N.W., Suite 928, Washington, DC 20005 or call Neva Duncan at (408) 923-4872.

August 8-12: *Contemporary Forums* will sponsor a conference entitled "Perinatal Controversies" in Jackson Hole, Wyoming. Contact Contemporary Forums, 530 LaGonda Way, Suite E, Danville, CA 94526, tel: (415) 820-2800.

August 23-26: The *Infant-Parent Institute* will present the 8th annual Brief Summer Course in Infant Mental Health on the campus of the University of Illinois at Urbana-Champaign. Case material will guide discussion on the nature of attachment in infancy, how families prepare for the arrival of a baby, problems of infant-parent "fit," and a particular theory and method of assessment and treatment. Michael Trout will be principal instructor. Contact Mr. Trout at the Infant-Parent Institute, 501 South, Champaign, IL 61820, tel: (217) 352-4060.

September, 1988

September 25-28: *Parent Care, Inc.* will hold its 5th annual conference in Newport Beach, California. The conference is designed for both parents and caregivers and will cover prenatal, neonatal, and post-discharge issues concerning the critically ill newborn. For more information call co-chairs Dottie Andrews or Ralph Rucker at (714) 532-8688.

September 29-October 1: The *Spanish Federation of Associations for the Help of Cerebral Palsy* will sponsor an international symposium in Madrid entitled "Cerebral Palsy, Its Educational, Therapeutic and Clinical Aspects." For more information, including possibilities for presenting papers and videos, call Dr. Carmen Aldave, (948) 25-50-11 or 25-10-99 or write to Camino de Santiago, S/N, 31190 Cizur Menor (Navarra), Spain.

September 30-October 1: The *C.M. Hincks Institute* and the *World Association for Infant Psychiatry and Allied Disciplines (WAIPAD)* will sponsor a multidisciplinary symposium in Toronto, Ontario on "Infancy: Intrapsychic and Interpersonal Life Cycles." Speakers and discussants will include Kathryn Barnard, John Byng-Hall, Peter de Chateau, Robert Emde, Yvon Gauthier, Serge Lebovici, Klaus Minde, Joy Osofsky, and Daniel Stern. Write or call Edythe Nerlich, C.M. Hincks Institute, 400 Jarvis Street, Toronto, Ontario M4Y 2H4, Canada, tel: (416) 924-1164.

October, 1988

October 6-9: The *Family Resource Coalition* will hold its National Conference in Chicago. Keynote speakers will include Edward Zigler, Bernice Weissbourd, T. Berry Brazelton, Anna Quindlen, William Julius Wilson, and Hon. George Miller. The conference will also include more than 100 workshops, half-day focus sessions, seminars, a video film theater, exhibits, and a program showcase. Write or call Family Resource Coalition, 230 N. Michigan Ave., Suite 1625, Chicago, IL 60601, tel: (312) 726-4750.

Zero to Three

Bulletin of
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A Community of Commitment: Parents, Programs and the Early Intervention Collaborative Study

by
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"In future studies we would be well advised to employ a comprehensive methodology including comprehensive approaches to both intervention and evaluation. That overall efficacy has now been well established at program termination allows us to get to more difficult questions about what kinds of approaches work best with what kinds of children, and with what kinds of effects."
Greenspan & White (1985)

"Our analysis clearly indicates that better designed and more varied approaches to the evaluation of intervention efforts are needed."
Dunst & Rheingrover (1981)

"Given that demonstration programs affect many constituencies that have a stake or say in the program's future, ways must be found to involve these groups or at least take account of their concerns in selecting outcome measures. Actual involvement is preferable."
Travers & Light (1982)

Most reviews of the literature on the efficacy of early intervention programs for children with developmental disabilities or delays and their families conclude with a recommendation for comprehensive, multidimensional, longitudinal studies. The persistence of this recommendation suggests a gnawing frustration with the methodological and conceptual limitations of existing research and acknowledges the increasingly pointed questions that are being asked about the long-

EILEEN POWELL

The Early Intervention Collaborative Study is supported by Grant MCJ-250522 from the Bureau of Maternal and Child Health and Resources Development and by a grant from the Jessie B. Cox Charitable Trust, Boston, MA.

Jack P. Shonkoff is the Principal Investigator of the Early Intervention Collaborative Study. Drs. Hauser-Cram, Krauss, and Upshur are Senior Research Associates on the project.

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National Center for Clinical Infant Programs *733 15th St., N.W., Suite 912, Washington, D.C. 20005* *(202) 347-0308*

term impacts of major public investments in early intervention programs. As the quotations above suggest, research designs must address complex rather than simple questions, be multi-dimensional in their selection of outcomes, and be responsive to the many constituencies of the programs investigated. However, the alchemy needed to translate recommendations for more sophisticated research into a "do-able" project remains elusive. Developing meaningful collaborative relationships with diverse "consumer groups" represents a particularly powerful organizational strategy.

Five challenges

Consider the five most common criticisms of early intervention research. First, previous studies of services provided from birth through three years of age have focused primarily on developmental change in children, with little attention directed to the adaptive characteristics of their families. Virtually no attention has been paid in program evaluations to ongoing interactions between these two domains, despite the recognition that development is a transactional process between a child and his or her family.

Second, studies of developmental change in children with disabilities have focused largely on differences in IQ or developmental quotient. Other domains of competence and behavior, such as problem-solving and social interaction skills, that may be more valid ecologically and linked more closely to specific service objectives, have been neglected.

Third, most research on children with disabilities and their families has focused on modal population characteristics (i.e., "the average child with Down syndrome" and "the typical parent of a handicapped child"). There has been relatively little empirical examination of differences among distinctive subgroups within these heterogeneous populations. The range of individual differences on key family variables such as education, income, and available social supports, and on such important child characteristics as severity of disability, health status, temperament, and behavioral style has been masked in most previous evaluation studies.

Fourth, research on children with disabilities has traditionally emphasized the identification of risk factors that predict poor outcome, with less attention directed to the elucidation of protective factors that predict positive adaptation for both children and their families. Rather than identifying individual strengths, most studies of children with disabilities, and particularly of their families, are based on a deficit model, in which the child's and family's positive or functional attributes are ignored.

Fifth, most longitudinal studies of children with disabilities and their families, including evaluations of service effectiveness have extended over relatively short intervals. Consequently, there are limited empirical data that address the stability of subgroup differences and the continuity of developmental adaptations over time. This constrains our knowledge of the long-term impacts of early intervention programming.

Zero to Three Staff
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Editors' Note

The articles in this issue of *Zero to Three* are about parents and research, and about parents and researchers. They describe how experiences of working directly with infants, toddlers, and their families suggest new questions for systematic investigation and spur the quest for objective measures that reflect the complexities of child and family development in the earliest years of life. The articles also tell us something about the ways in which research findings can guide the improvement of practice.

What is remarkable about the articles in this issue is their emphasis on parents. Perhaps now that it has become respectable to assert that infants are competent, active shapers of their lives and environments, we can also attribute these qualities to parents. Thus **Jack Shonkoff** and his colleagues describe the roles of parent participants and a Parent Advisory Board in shaping the design and implementation of a major longitudinal study of early intervention with infants and toddlers with disabilities and their families. **Megan Kirshbaum**'s descriptive research represents the kind of investigation needed to break ground in a new area of inquiry. In the course of her pioneering research on the interaction between physically disabled parents and their ablebodied babies, she has drawn on the expertise and problem-solving ingenuity of many disabled parents, not only to participate in the research but also to develop resources and services to support those families who are extremely stressed. **Mary Beth Bruder** and her co-authors describe another kind of research—the "model demonstration grant"—and how early collaboration between professionals and parents in observing at-risk newborns provides not only a non-intrusive service to families but also a promising approach to case finding for early intervention services. Finally, **Terry Bond** describes an initiative sponsored by the National Council of Jewish Women's Center for the Child, in which the field researchers are volunteers, (many parents or grandparents themselves), amassing policy-relevant data on parental leave and child care for working parents of infants. Such research could not be more timely or relevant to the formation of public policy.

In order to address the first criticism—the absence of family outcomes in previous research—greater specificity is needed regarding the areas of parental and family life that are expected to change as a result of participation in an early intervention program. Most service providers assume that their efforts affect a range of family characteristics such as parenting stress, social support, parent-child relationships, or adaptive family functioning. In the past, however, many have not articulated explicit goals for families. The new federal requirement for individualized family service plans under PL 99-457 should stimulate more systematic evaluation in this area. However, the development of valid measures of these family attributes and functional characteristics is in its infancy and many of the more widely used instruments may not be sensitive to all of the subtle as well as dramatic changes that occur over time.

In order to address the second criticism—the reliance on IQ or developmental quotient as the sole outcome measure for children—researchers must confront persistent questions regarding the reliability and validity of appealing alternatives to traditional measures. If IQ is abandoned as the primary criterion for effectiveness, on what basis should other outcome criteria be selected? Given the diversity of children served in early intervention programs, each with presumably individualized service goals, the range of relevant outcomes often appears to be too unwieldy for any single investigation. In addition, measures of many important aspects of child development, such as attention, motivation, and peer relations, are not as well developed as standardized measures of IQ.

Although the selection of appropriate measures haunts all research endeavors, longitudinal studies are plagued additionally by the lack of comparability of instruments administered at different ages. Even when limited to well-known measures, such as IQ, certain aspects of development (such as psychomotor skills) are weighted more heavily in instruments used for infants whereas other domains (such as language and memory) become dominant in the evaluation of preschoolers. This lack of continuity in developmental domains for preschoolers compared to infants applies to most measures, although the properties of instruments other than tests of IQ are less well known. Thus, if innovative child measures are used, as they should be in longitudinal research on children with disabilities, their selection involves an element of risk.

In order to address the third criticism—the need to study individual differences in development—researchers need access to large numbers of children and families. Thus, reliance on a handful of early intervention programs for sample recruitment is generally insufficient, particularly if the target groups and subgroups are to be tightly defined. Gaining the cooperation of multiple and independent early intervention programs requires a substantial up-front investment of time and trust-building even before funds may be available to conduct the research. While most early intervention professionals are keenly aware of the need for comprehensive, longitudinal studies of the effects of services on children and families, the demands of a research project (even if limited in scope) must be absorbed within a workload that is already overtaxed. For example, obtaining standardized information on services provided to children and families requires additional work for program staff.

The development of data collection strategies that are consistent and standardized yet sensitive to the diverse organizational structures within service programs poses innumerable dilemmas in research design. Maintaining relationships with programs over extended periods of time, while they remain blind to the study's hypotheses, requires a great deal of continuing attention, particularly given the realities of staff turnover and the length of time that must pass before the lessons from longitudinal research can be learned and applied. Thus, the durability of the initial motivation of service programs to be supportive and cooperative can never be taken for granted.

In order to address the fourth criticism—the need to examine protective factors in child development—researchers have to cast a wide conceptual net that reflects multiple (and often unverified) theories of human development. The risk of being accused of engaging in a "fishing expedition" always looms over those who attempt to explore less navigated waters. Most funding agencies respond with greater enthusiasm to tightly conceptualized studies than to ambitious projects that propose an intellectually broad (and often expensive) exploratory investigation.

A wider net of variables also means more extensive data collection. Participants in broad-based studies are asked more questions, complete more questionnaires, are contacted more frequently, and usually are given little or no direct feedback about the study's findings for many years. Thus the careful researcher must ask: At what point are the demands of a comprehensive study too burdensome for even the most enthusiastic research "subjects"? Further, what strategies are available to research teams to sustain the goodwill and trust of people who do not stand to gain immediate personal benefits from their participation?

In order to address the fifth criticism—the need for long-term studies that can address the durability of program effects— researchers have to retain their sample for years (not months) against considerable odds. People move, lose interest in participating, experience too many other demands on their time, and become impatient for results or lose faith. Even if a sample can be sustained, long-term research funding is a rarity. Funding agencies must be willing to support a project with a "venture capital" spirit to their investment. The current climate of fiscal restraint among public and private sources of research dollars can easily deflate the ambitions of both investors and applicants. Finally, even if the sample is sustained and funding is secured, keeping a research group intact over such long and critical stretches of the members' professional careers requires a precious chemistry within the team. Thus, the sheer logistics associated with the implementation of longitudinal research requires a level of personal and professional commitment that is often underestimated.

One project's experience

When the Early Intervention Collaborative Study (EICS) was in a preliminary "talking stage" (1983-1984), the core research staff shared a set of basic convictions about the scope of investigation needed to assess the effectiveness of early intervention services but we had no detailed map with which to plot the route. Our initial goal was to answer definitively the question, "What types of early intervention services are most effective for what types of children and families?" We have not yet deviated from that goal. However, we have become increasingly respectful of the complex infrastructure needed to address that question.

> *Our initial goal was to answer definitively the question, "What types of early intervention services are the most effective for what types of children and families?" We have not yet deviated from that goal. However, we have become increasingly respectful of the complex infrastructure needed to address that question.*

Our organizational strategy was designed to operationalize the *collaborative* nature of the project. We realized that in order to be responsive to the many legitimate interests in the development of early intervention programs, we needed ready access to a diverse set of constituencies: early intervention policymakers, program representatives, clinicians, politicians, academic researchers, and families receiving services. Consequently, we created a number of advisory groups as a mechanism through which our needs for assistance and guidance could be met. Our goal was not to form the obligatory "Advisory Board" that all good grant-funded projects must have; rather, we hoped to establish a community of committed individuals who would guide, advise, and react to the evolution of the project.

Over the past four years, we have learned that projects (such as ours) not only require the collaboration of multiple constituencies but also become the recipients of collective aspirations. The "costs" of these aspirations to the independence of our research team are balanced by the creative input and reinforcement we have received in our continuing refinement of the study's design, procedures, and measures. For example, methods to measure complex variables (e.g., mastery behaviors, peer interaction) have been incorporated into our protocols with the support of our many advisors, despite the fact that these new measures may be considered "risky," "still under development," or "not well established within the research community." Our goal of including such promising, state-of-the-art measures in the study was reinforced by the deep convictions of our advisors that "safe" reserach was unlikely to produce the kind of information needed in this field.

Most people who conduct longitudinal studies can name critical events, people, or situations that were particularly influential and that propelled them to stick with their project over an extended period of time. The Early Intervention Collaborative Study is no exception. Originally planned as a three year investigation of the impacts of early intervention services on three groups of children and their families, the study has now entered a second phase in which the 217 children and families who were enrolled in Phase I will be followed until each child is five years old (see box for a description of the study). Among the catalysts for the extension of the study were two unique groups of parents: our Parent Advisory Board and the parents who are participating in the study.

The idea of a separate Parent Advisory Board was developed during the early planning stages of the project. Our initial expectations were straightforward: we wanted to ensure that the scope of our study would be responsive to the concerns of families who are recipients of early intervention services. What we did not expect was the critical role the Board has played in shaping our commitment to studying children and their families in ways that had not been included in previous early intervention research. At our first meeting, for example, we asked Board members about their goals for their own children in early intervention programs. Their responses had little to do with increments in their childrens' IQ scores but rather involved the development of social skills, problem-solving behavior, and independent functioning. We asked about their goals for themselves and their families. They indicated a desire to be better "readers" of their children, to be better informed about their children's development, and to be better prepared to obtain required services. While these responses were consistent with the criticisms expressed about the types of child outcomes used in most previous early intervention research, they also served to validate the choices we were making in the selection of our study variables.

The Parent Advisory Board pointed out to us that participation in a study offers parents an opportunity to give something freely at a time when they often feel they have to ask for so much, and a chance to contribute to the development and expansion of early intervention programs.

The EICS Parent Advisory Board has educated us in many ways. In the early planning stages of the project, we worried about how we might stimulate the interest of families to participate in a study from which they would receive no individual feedback, despite lengthy in-home evaluations of their child and innumerable questions of themselves. The Board's response was enlightening and encouraging. They pointed out that participation in a study offers parents an opportunity to give something freely at a time when they often feel that they have to ask for so much. They also noted that most families are extremely grateful to have services available to them and that many would welcome the chance to contribute to the development and expansion of such programs. Thus, we had not anticipated that our central concern—the absence of direct, personal gain for participating families—would, in fact, be a positive motivation.

The Early Intervention Collaborative Study

The Early Intervention Collaborative Study is a longitudinal investigation of the development of 217 children with disabilities and their families. In Phase I, children and families were recruited for the study at the time of their enrollment in one of 29 participating early intervention programs in Massachusetts and New Hampshire. In-home observations and interview information was collected from participating children and families within one month of program entry and again 12 months later. Phase II of the study consists of in-home assessments of children and families within one month of the child's third and fifth birthday. Information concerning early intervention services is collected on a monthly basis. After placement in a preschool program (usually around age three years), information from the child's teacher is obtained and a classroom observation of the child is conducted. The teacher questionnaires and classroom observations will be repeated at age five.

Phase I of the study was designed to investigate the relative merits of describing children by type of disability versus the level of severity of their disability; the relationships among specific child and family variables; and the differential effects of specific services. Phase II focuses on the stability of the initial effects of early intervention services; the identification of predictors of child competence and family adaptation during the preschool period; and the short-term effects of the transition from early intervention to preschool services on children and families. Child outcomes investigated include mastery skills, adaptive/functional skills, psychomotor/cognitive skills, maladaptive behaviors, and interpersonal skills. Family outcomes include parenting stress, effects of the disabled child on family life, mother-child interaction, parental adjustment to the child's preschool entry, and sibling relationships.

The sample includes 60 children with Down syndrome (mean age at entry to the study is 3.5 months), 80 children with cerebral palsy/motor impairment (mean age 11.5 months), and 77 children with developmental delays of uncertain etiology (mean age 16.2 months). Almost a quarter (24%) of the families have an annual income below $10,000 and a third (34%) have an annual income above $30,000. About a fifth (22%) of the mothers are unmarried; 35% work full or part-time; and 50% have a high school education or less.

Sample recruitment and initial assessments have been completed for 217 children and families. As of Spring, 1988, about half of the study sample has also completed their second home-visit assessment. A small group of the oldest children and their families who have made the transition into preschool services have also entered Phase II of the study, which involves a home assessment at age 3 years, followed by data collection from the preschool teacher and a classroom observation. Phase I will be completed by June, 1989. Phase II will be completed in 1992.

The role of our Parent Advisory Board has extended far beyond conceptualizing study outcomes and anticipating family reactions to the project. They have been active contributors to the technical quality of the study by specifying issues to investigate and reviewing study questionnaires. Every question asked of a parent in the study has been screened by our Parent Advisory Board for clarity and relevance. Several of the fathers on the Board emphasized the importance of capturing paternal perspectives about rearing a child with disabilities, thereby underscoring the relative lack of knowledge about fathers' views and contributions. Indeed, the development of several new measures (e.g., a rating scale to assess the quality of the relationship between the parent and the early intervention case manager) was influenced heavily by parent input.

Parents encouraged us to think about those factors that affect the durability of the impacts of early intervention. How parents both influence and adapt to the transition from a fairly personalized service system to a large and more multi-faceted system are critical issues.

Parent advisors also assisted in training our field staff. They reassured our data collectors that the questions they were to ask and the procedures they were to follow were not overly intrusive to families. They reminded our staff how much parents of children with disabilities enjoy seeing their child played with and receiving affection as one would with any non-disabled child. They relived their own feelings and reactions during their initial entry into early intervention programs and conveyed a vivid portrait of the range of emotional and physical capacities of our prospective study sample members.

The EICS Parent Advisory Board was also among the most vocal in encouraging us to continue to follow our sample into the later preschool years. At the study's inception, the Board members all had children enrolled in early intervention programs (although none were members of the study sample). As the project progressed, their children graduated from early intervention and entered preschool programs. With the change in services, Board members developed new perspectives on the benefits they had accrued from their involvement in early intervention programs as well as on the impact of the service transition process itself. Since these perspectives varied greatly, they encouraged us to think about those factors that affect the durability of the impacts of early intervention. How parents both influence and adapt to the transition from a fairly personalized service delivery system, such as early intervention, to a large and more multi-faceted system, such as the public school, are critical issues. Although we were well aware that questions of the long-term effects of early intervention services are compelling for policymakers, practitioners, and developmentalists, our Parent Advisory Board reminded us of the particular value to families of pursuing these concerns.

The parents who participated in Phase I of the study provided an additional, although somewhat unexpected catalyst for our plans to continue. At the end of the second home visit (which marked the expected termination of data collection), many parents asked spontaneously if we would return, adding that they certainly hoped we would. We soon realized how much these parents valued their participation in a research project, even though they did not stand to gain any direct feedback about themselves or their child. We attributed this feeling to the care and sensitivity of our research field staff who gave parents the freedom to discuss their child and themselves at length. The families enjoyed sharing their experiences and describing the changes in their children since our first visit. Their responsiveness conveyed an enthusiasm for the project that was gratifying to the entire research staff. The feasibility of "retaining" a carefully selected sample of families from whom we could learn a great deal about the development of children with disabilities and the adaptation of families over time was evident.

Answers to fundamental questions concerning the efficacy of early intervention services for children with disabilities and their families will require numerous investigations that are rigorously designed to address very specific questions. No single study will be definitive. The logistical and technical challenges of designing and implementing sophisticated research are formidable. Along the way, the staff of the Early Intervention Collaborative Study has learned about the sturdy yet delicate infrastructure that is required to establish and maintain a cooperative working relationship with participating early intervention programs and the families they serve, the strategies needed to wrestle with important theoretical and measurement issues, and the on-going administrative task of securing continuous funding and support from public and private resources. Among the core elements of this multi-faceted infrastructure is our Parent Advisory Board, which has contributed so much to the substantive and technical quality of the project, and the families who have given so generously of their time and experiences.

The ultimate beneficiaries of research projects such as ours—the families who are served by early intervention programs—are an often untapped resource to researchers. We hope that our description of the EICS Parent Advisory Board will encourage other investigators to develop similar opportunities for such collaboration in future reseach activities.

References

Dunst, C.J. & Rheingrover, R.M. 1981. An analysis of the efficacy of infant interaction programs with organically handicapped children. *Evaluation and Program Planning* 4, 287-323.

Greenspan, S.I., & White, K.R. 1985. The efficacy of preventive intervention: A glass half full? *Zero to Three*, 5, 1-5.

Travers, J.R., & Light, R.J. 1982. *Learning from experience: Evaluating early childhood demonstration programs.* (Report of the Panel on Outcome Measurement in Early Childhood Demonstration Programs, Committee on Child Development Research and Public Policy) Washington, D.C.: National Academy Press.

Perspectives from the EICS Parent Advisory Group

In preparing this article, the authors invited members of the EICS to respond to two questions, one concerning their perceptions of researchers, and/or the research process, the second concerning their own participation in EICS.

In what ways has your participation in the EICS Parent Advisory Group changed your perceptions of researchers and/or the research process?

"As a member of the academic community, I am fairly familiar with research techniques; however, my own field of research is the humanities, a far cry from the nature of the research on this project. I have been fascinated to observe the methods for data collection, as well as the collegial efforts of the researchers. The staff was scrupulous in its efforts to avoid prejudicing the data by careful working of questions, for example, but at the same time mindful of the emotional dynamics in the families being studiesd I saw this sensitivity in the careful preparation the staff undertook with their field researchers. They chose skilled and sensitive individuals, and then spent a good deal of time orienting the field researchers to the specific task of data collection for this project. The Parents Advisory Group was invited to one of the training sessions, where we gave feedback on how the researchers might approach families with the questionnaires and what they might discover about differences in responses by the families. Throughout the project, Dr. Jack Shonkoff and his colleagues on the study have been very receptive to the comments from the Parent Advisory Group. Occasionally we voiced dissatisfaction about the wording of questions or the direction the study was taking, and our comments were always heard and often heeded by the team of investigators."

—Linda S. Wells

"Researchers have been burdened with the stereotypical reputation for being dry, unfeeling, and analytical in their style of dealing with people or problems. To my pleasant surprise, I found the staff members of the EICS to be open, caring, professionals who were not defensive or exceedingly protective of their program when confronted with critical remarks by parents. Some individuals affiliated with professional helping agencies I've experienced to be very quick to label parents as suffering from emotional problems related to their inability to properly 'come to terms with', or accept, their child's disability. These remarks have surfaced when parents raise critical issues regarding some aspect of programming or service delivery. It is very refreshing to participate in a forum that gives me the feeling that my thoughts and opinions are valued and important to the success of the study."

—Frank Galligan

What have been the most enduring personal benefits to you of participating in EICS?

"My son, Dominic, who has Down Syndrome, has quite literally grown up with this study. When I began to serve on the Parent Advisory Board, Dominic was in an excellent early intervention program here in the Boston area. My experiences with our early intervention program gave me some valuable insights into the new expectations that professionals had developed for children with Down Syndrome over the past few years. Translating my insights and adjustment problems into another context, the EICS, and utilizing these perceptions in the study made the overall adustment to Dominic's disability much easier. I felt that I was perhaps helping future parents of disabled children by my participation in this study, however small the contribution may be. Having a disabled child causes parents to feel helpless, at least initially, but being asked to participate in such a research project as the EICS empowers those parents because they feel they may be helping others who face similar crises."

—Linda S. Wells

"Participating on the Parent Advisory Board for the EICS initially gave me a shot of confidence at a time when my self-esteem was drained. Working with professionals, to make an impact, on a research study that will have wide-reaching positive implications for special needs children and their families, makes me feel useful and in a unique position to help many children and families. In a rather strange fashion, the sharing of this experience with researchers (who are in a powerful position to ultimately influence future service delivery) can give my child's and families' pain a more positive meaning.

Another benefit of participating in EICS is the opportunity to develop more positive interpersonal relationships with parents and staff members who join with you in working towards some common goals.

There is a special sharing of goodwill within the group. For me, it could be compared to happening upon a group of people in a foreign land who share your language. The 'support group' dynamics interplay with the 'empowering' dynamics of feeling that my special input is valuable to a whole future population of special needs families, to make for a powerful, enduring personal benefit."

—Frank Galligan

Parents With Physical Disabilities and Their Babies

by
Megan Kirshbaum, Ph.D.
Executive Director, Through the Looking Glass

Through the Looking Glass staff's clinical work with disabled parents dates back 14 years, with a focus on this population for the past 6 years, since the founding of the agency in 1982. We are at this point experienced with more than 125 families with at least one disabled parent. The disabilities have ranged from mild to severe, including a wide variety of causes such as spinal cord injury, post-polio, cerebral palsy, rheumatoid arthritis, arthrogryposis, spina bifida, osteogenesis imperfecta, amputation, etc, including invisible conditions such as seizure disorders, progressive illnesses such as multiple sclerosis, and the sensory disability of blindness. Cognitive disability is also dealt with, but is not the focus of this paper.

The nature of the work with these families has also been diverse. It has included an interviewing project focused on pregnancy and birthing (including also deaf parents), the first research on the interaction of physically disabled parents and their ablebodied babies, and resource development, including adaptive parenting equipment and videotapes. A national newsletter for disabled parents and the professionals working with them will be launched in September, 1988. Since Through the Looking Glass is an infant mental health program, the primary focus has been on services. The disabled parents involved with us have an extremely wide spectrum of capabilities, from well-functioning disabled parents who are willing to participate in the research with their babies in order to help other such parents and professionals; individuals desiring only information and contact with other disabled parents; disabled parents requesting short-term intervention—e.g., assistance with adaptive strategies and equipment so they can work out the physical care of their baby; people wanting to work on emotional issues arising during the consideration of pregnancy or adoption, during pregnancy or after parenting; to multi-risk families who would require intensive and longterm services aside from parental disability. It is important to note that some of the most physically disabled parents have fallen in the category of well-functioning parents being videotaped, while some of the multi-risk parents have had very mild physical disabilities. The variety of people has provided perspective crucial to refining clinical assessment and intervention. It has meant that via our interviewing and research projects we could draw on the expertise and problem-solving ingenuity of many disabled parents in order to develop resources and services to support those families who are extremely stressed. We are pleased to begin communicating some of their and our experience to you.

The context of the work

Through the Looking Glass, located in Berkeley, has focused on preventive services, professional training and research concerning families and babies where there is a disability or medical issue in either parent or child. It emerged from longterm psychotherapeutic work with disabled people of all ages and their families. It has attempted to provide a bridge between the adult disabled community and the parent and professional communities concerned with disabled infants. The service model has developed under the auspices of three National Institute for Disability and Rehabilitation Research Innovative Grants, and has integrated infant mental health, family therapy, developmental/educational and peer counseling approaches. The meaning of 'peer counseling' here is unusual; it refers to our direct service staff having parented medically at-risk or disabled babies, or being themselves disabled, in addition to being professional clinicians. The program has been evaluating the impact of direct services as well as training of other professionals (concerning families and babies with disability issues) being provided by such dual-role individuals. The staff is multi-ethnic and the clientele is socio-economically and ethnically very diverse. The setting is a small community agency with a staff of 8 part-time clinicians and developmental specialists and 3 consultants. Services are provided primarily during

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home visits, with 4 support groups, and office visits as an option. Last year, approximately 500 professionals received training and 53 families received direct services. As is usual, approximately half of our client families had at least one parent with a disability.

A conceptual focus of all our work has been the exploration of a nonpathological model, as contrasted to a deficit or medical model, in the provision of services to families and babies with disability issues. This enterprise has been challenged by the increasing numbers of multi-risk families we serve—51% last year. We've been trying, in general, to find ways to inform the infancy and "special infancy" fields with the accumulated experience of family members, as well as a more life cycle and adult disabled person perspective.

Our longterm interest in 'peer counseling' is reflected in the approach to research, services, resource development and training regarding parents with physical disabilities. The accumulated knowledge of experienced disabled parents is being documented and analyzed, utilized to benefit expectant and new parents with disabilities. Through research participation, videotapes, informal networking and a support group, veteran disabled parents are able to assist and be mentors or resources for inexperienced ones.

Motivation for this work

There were social considerations in our decision to focus on resources for disabled parents. In the San Francisco Bay Area, specifically Alameda County, there is a particularly large disabled adult population, with estimates as high as 17-20%. Because of the strength of the independent living movement here since the early 1970's, many young disabled people have gravitated to the area. Integrating into the community, forming relationships, becoming sexually active, expecting a full life are leading to a rapid increase in the number of disabled parents. It appears that the trend is nationwide, with an earlier concentration in this region. This has meant an urgent local need for services, as well as an opportunity to develop a model service delivery program, and to initiate research serving disabled parents.

In 1984, for a chapter in a maternity nursing textbook a literature search and extensive interviewing were done on disabled people's pregnancy, birthing and parenting. We found the existing literature to be remarkably scarce, and, from a disabled community point of view, often attitudinally negative and pathological in emphases, language, or hypotheses chosen. Assumptions tended to be made about analogies between mental illness and physical disability, without significant familiarity with the latter. Speculations, however interesting, were not grounded in clinical or fieldwork expertise with physically disabled adults. Some interesting retrospective work had been done with adult children of spinal cord-injured and deaf parents, but observational studies of interaction during infancy seemed virtually nonexistent. A notable exception was some excellent work concerning deaf parents and their babies. Practical material for professionals and parents was also scarce.

In our interview project, disabled parents reported many difficulties with perinatal professionals and settings. Examples included inaccessible bathrooms on a labor or delivery floor, interference with the role of an interpreter during labor, asking a paraplegic pregnant woman to stand 'for just a minute' on a scale, the aggressive pressuring for abortion. Sometimes medical professionals in even high-risk obstetrical programs were unfamiliar with basic rehabilitation knowledge. Physicians frequently had to 'wing it' because there was no literature on birthing for a particular disability. It is common for disabled pregnant women, with or without a physical basis for concern, to question whether their bodies can indeed work to have a baby. They were acutely aware of their physicians' doubts about this. And given their sophistication about their own disabilities, the anxiety was increased by lack of ordinary disability expertise in their medical providers. Given this situation, some of the most successful relationships with medical providers involved a kind of collaboration in which the woman's knowledge of her own body and functioning was acknowledged and respected. Yet many disabled people interviewed—a competent and articulate group—reported it was common for professionals to question their ability to care for their babies, including their awareness of the babycare implications of their own disability. This was often felt to be offensive and undermining of their parental self-esteem at the outset. Unfortunately most professionals did not have the experience nor were there community resources to facilitate physical care where there were indeed difficulties. Unfamiliar with how disabled adults lived independently in the community, some professionals found it hard to envision the situation of a disabled person caring for a dependent baby.

Professionals' lack of images of well-functioning disabled adults, outside of patient roles in medical settings, was combining with disabled parents' self-doubt in a problematical way. It is important to note the extreme lack of role models for parents with disabilities. Disabled children seldom had grown up with *any* images of parents with disabilities. To appreciate the impact of this on parental self-esteem it helps to imagine what it would have been like to become a parent, never in your life having seen an ablebodied person caring for a baby. One blind mother reported meeting the first other such mother when her own child was five. In addition it was usual for this generation of disabled adults to have been socialized as children in such a way as to assume their asexuality; often in therapy it is reported that childhood play or talk concerning marriage and parenthood was redirected or discouraged.

Our community and clinical experience with disabled parents suggested that an accurate and nonpathological documentation of the wide spectrum of capability of disabled parents needed to include ordinary parenting, not just to report on the most stressed families, e.g., those in contact with protective services, or receiving services in mental health clinics.

We decided that the first step of such research was to describe and document, to provide videotape images where these had been lacking. Because of the common questioning of capacity for physical care we chose to begin by documenting such care. Funded by National Easter Seal Research Foundation we began the first study of the interaction of physically disabled mothers and their ablebodied babies. This has involved videotaping and analyzing basic care (feeding, bathing, lifting, dressing/diapering) from birth through toddlerhood—focusing on how the mothers and babies collaborate together over time in working out adaptations to the disability. The 3-year study, to be completed after this paper is published, has been providing hundreds of hours of powerful videotapes—images for disabled parents and the professionals who work with them.

Our study has been providing hundred of hours of powerful videotapes—images for disabled parents and the professionals who work with them.

Ethical, clinical, cultural issues—practical dilemmas

As clinicians who were also members of the disabled community we were very familiar with local disabled people's wariness of professionals, concern about disability attitude and exploitation on the part of anyone purporting to do a 'study'. There was a particular vulnerability felt in the area of parenting, often with anxiety about potential 'removal', or self-demands for perfection. The Bay Area disabled community is essentially a cultural group, with subgroups (e.g., deaf, blind communities, Little People). Individual disabled parents vary as to the degree to which they are integrated into or isolated from this culture. In general the community is highly politicized, in terms of disabled independent living movement or disabled civil rights issues. Work in this community, for ablebodied, nonfamily members, is cross-cultural in nature, with all the complications that implies. It appears that my husband, Hal Kirshbaum, who is the disabled father of our children, and myself, were allowed to do this videotape study partly because we were peers. We appreciate the responsibility of this trust. To balance what one might expect to be our positive bias and our clinical perspective, a researcher from outside the community has been involved—Frances Knudtson—and outside videotape coders have been utilized.

To give you some examples of the practical dilemmas faced: The research was envisioned as presenting a contrast between infant/parent interaction during basic care, contrasting the disabled mother to an ablebodied caregiver. We had observed, during clinical work, babies of disabled parents making early distinctions between ablebodied and disabled parents, and behaving less cooperatively, exhibiting fewer adaptations, with ablebodied caregivers. Each visit we tried to capture the supposed contrast during videotaping. However, we found that some disabled parents were opposed to having ablebodied people participate in the early care in any way, out of a determination to accomplish this themselves. Others were concerned that the videotaped contrast of an ablebodied caregiver might make their own care appear to be lacking. Others did not have such assistance available. Recently we have found some parents that believe the early involvement of ablebodied caregivers will interfere with their baby's adaptation to their care.

As clinicians we found that with 3 out of the 10 families videotaped, it was necessary to intervene to different degrees. This small group will be described as a subgroup within the study. Services for disabled parents are so scarce that it was clearly unethical to withhold our expertise. Also some disabled parents needed to or chose to become, exclusively, recipients of services rather than study participants.

Summary of the videotape research: 'Learning From Mothers with Physical Disabilities'

This study is the first documentation of and preliminary analysis of interaction—the reciprocal process of adaptation—as it develops between 10 mothers with a variety of physical disabilities and their ablebodied babies. As exploratory hypothesis-generating research it is intended to begin to provide a descriptive baseline for subsequent research and/or interventions. Researchers in parent/infant interaction and clinicians in the infant mental health field have some working sense of a range or spectrum of "good enough parenting". This study attempts to reconceive or enlarge that sense so that it allows for and considers issues concerning physical difference in mothers. Included is the first systematic research on adaptive devices, strategies and modifications pertaining to physically disabled mothers. The outgrowth of observations during clinical work, the original questions to be investigated were: 1) How can one describe the developmental course of infants' adaptation to their mothers' physical disabilities?; 2) How does the mother facilitate the adaptation of the infant to her disability? In what respect does the infant adapt? How can one describe the dance between disabled mother and infant—the mutuality, reciprocity as it occurs in caretaking and play?; 3) How do adaptive devices, strategies and modifications fit into the unfolding reciprocal adaptation?; 4) What contrasts are seen with different disability situations?; 5) Is there a difference in the infant's behavior with the disabled mother versus the ablebodied caregiver?; 6) How do these other questions address the disabled mother's effectance, competence and power in the interaction? What sort of solutions, inventiveness maximizes this effectance?.

Based on clinical observations it was hypothesized that adaptive reciprocity is facilitated, at least in caretaking, by the following sort of sequence between disabled parent and baby: indicated or signaled intention and incomplete actions on the part of the disabled parent that invite mobilizing or cooperation by the infant. It was expected that this sequence developed over time. The approach involved videotaping primarily basic care, feeding, bathing, dressing/diapering, lifting/carrying regularly from 2 weeks of age through 12 months or walking. The most detailed level of analysis of the videotapes has required the development of our own coding system. This coding system has pinpointed various categories and patterns that are, we believe, useful for clinicians and educators. Since the results of this study will not be completed until after the publication of this paper, I would like to focus on what we have learned from the outset, what has been practical in terms of services, and has already seeded other aspects of our program.

Impact of the research on clinical work and program model development

The study has been documenting babies' extremely early adaptation to their physically disabled mothers. It has been trying to discern and describe just how this comes about. For instance, the first mother we videotaped has paraplegia due to spinal cord injury. To deal with her difficulties with trunk balance, that is, to prevent falling from her wheelchair during babycare, she invented a way of lifting her baby with one hand. When the baby was one month old, she would signal him by tugs on the front of his clothes, pause while estimating his readiness by his physical response, and lift him by the clothes. At one month of age he would adapt by curling up like a kitten and remaining very still and compact during the lift. The mother demonstrated how she had very gradually been working on developing his ability to hold up his head during the lift. One month later, when he was physically more capable, we documented that when drowsy during the lifts he didn't do his part of the job as effectively, letting his head fall back more, moving too much, being less compact. His mother explained and demonstrated how he needed to be roused to cooperate. We have edited this mother and baby's tapes to show the differences in signaling, facilitation of the baby's ability to cocoperate during lifting as this develops over time.

In our subsequent research and clinical work it is not unusual to observe such clear adaptation as early as one month of age. It takes other forms later: One mother with multiple sclerosis, using toys initially to entice, successfully teaches a crawling baby to consistently come to her when called. An active and mischievous toddler lies still during a long diapering by her blind father, but is resistant and struggling from the outset with her sighted mother. Another toddler distinguishes between the safe home environment, where some teasing and testing may be done, e.g., lying flat on the floor so it's difficult for a parent in a wheelchair to get him—and public places, where the child cooperates by consistently staying close to the parents, e.g., holding his or her hand. Many parents utilizing wheelchairs find their toddlers heavy to pick up, so elicit cooperation, typically through talk and signaling ('ready? 1-2-3'), encouraging them to stand on the footrest and assist by climbing.

We have found episodes of lifting especially salient, concise examples of the collaborative adaptation. In addition to looking at signaling and otherwise indicating intent, we are looking at whether (at least some) parents who are especially effective in eliciting cooperation use a kind of 'staging' technique—where they break down even the small task of lifting into smaller components of positioning, often interspersed with rewarding moments of relating to their baby.

When a parent has upper body involvement in his or her disability, such as with severe cerebral palsy, dressing and diapering can be a very slow process. Again we are trying to describe and analyze what goes on between the dyad during this care. How is it that some mother/baby couples negotiate the prolonged task so pleasantly, while for others it becomes a battle of wills exacerbated by the physical difficulties and slow pace? For instance, to what extent is the mother reading her baby's state and using a sequence of techniques to elicit and maintain her baby's patience, such as talking, sound play, offering of toys or objects, pacifier or bottle, interspersing the task with relating or play, etc.? Might this diapering/dressing present a microcosm that will be informative about longterm parental effectance, ability of the parent to 'manage behavior' in a way that serves the infant/parent relationship?

It is not unusual to observe babies clearly adapting to their physically disabled mothers as early as one month of age. For one infant, this meant curling up like a kitten and remaining very still and compact during a lift.

The issue of slow pacing during care is of more general importance. In many families a slow tempo is more of a general characteristic. In our local disabled community in-jokes are made about 'crip time', referring to a relaxed, slow-paced approach to life (and work). One might consider it a cultural difference. I suggest it actually has some potential advantages for babies, and may be functional in the sense of maximizing their opportunity for cooperation.

As mentioned before, since 1985 NIDRR's Innovative Grants have funded TLG's model services and resource development for disabled parents, as well as training to professionals regarding this population. This has made it possible to promptly apply and disseminate the findings of the Easter Seal study, to provide services when these were required, to develop other needed resources, and to pursue ideas generated by the original study.

For instance, in videotaping families in the Easter Seal study we observed disabled parents making decisions about whether or not they (alone) would do a type of care that we would call particularly 'adaptively stressed', or difficult in terms of the disability. It would be possible with the use of adaptive equipment and teaching to work out a way for a mother with cerebral palsy or with rheumatoid arthritis affecting her hands to give a bath to her baby. But this might feel too stressful and arduous and a mother might choose to have an ablebodied partner or other caregiver do the task. One middle-class mother with severe cerebral palsy (part of the Easter Seal study) chose, whenever possible, to use attendants to do even diapering. She was capable of diapering but chose to spend her time with her baby more pleasantly. However, our tapes document how she maintained (we infer) a central psychological role in the eyes of her baby, orchestrating the attendant's physical process and relating to her baby throughout. The most severely disabled parents, who must rely (to different degrees) on attendants or other caregivers to provide physical care, often have concerns about how they can maintain the parental authority. Offering the viewing of these 'mentors' videotapes , conveying or letting them directly tell their stories (e.g., as part of a support group), is a potent part of the clinical work on this issue. A confounding and critical social problem, however, is the lack of public funding for in-home baby care for severely disabled low-income parents. Therefore, the solutions arrived at by middle-class parents may not be at present an option for those with low incomes.

We observed disabed parents making decisions about whether or not they (alone) would do a type of care that would be particularly difficult in terms of the disability. Some parents "orchestrate" an attendant's physical process, relating to their baby throughout; teamwork between two disabled parents or one disabled and one ablebodied parent or other caregiver is also common.

Teamwork, between two disabled parents or one disabled and one ablebodied parent (or other caregiver), is commonly documented by our videotapes. Our knowledge of this teamwork during care is often integrated into couple and family work. To give you a small sample of what this is like: A family was referred to us with a failure to thrive, extremely irritable one-month premature baby. Related to the father's gradual progression to blindness there was a general pattern of over-functioning by the sighted wife and under-functioning on the part of the husband. He was thought by the wife to be completely incapable of caring for the baby. This was the center of enormous conflict, enacted by arguing and shouting at one another during this extremely sensitive baby's basic care. Due to the sighted mother's fastidiousness the diapering was extremely prolonged, and the baby was regularly building up to a peak of crying that was exhausting and alarming. One of the earliest interventions with this family was to get them to channel their disputes into times when they weren't handling their baby (framed as to help his digestion). During the sessions we, instead, experimented with their working as a team—e.g., the father soothing the baby with the containment of his hand on the baby's chest while the mother diapered. Thus the changes were less prolonged and stressful for the baby, and the experience of helping their baby together was seeded. This is only a fragment of longterm work which involved dealing with a history of cumulative losses, teaching parenting adaptations to blindness, etc.

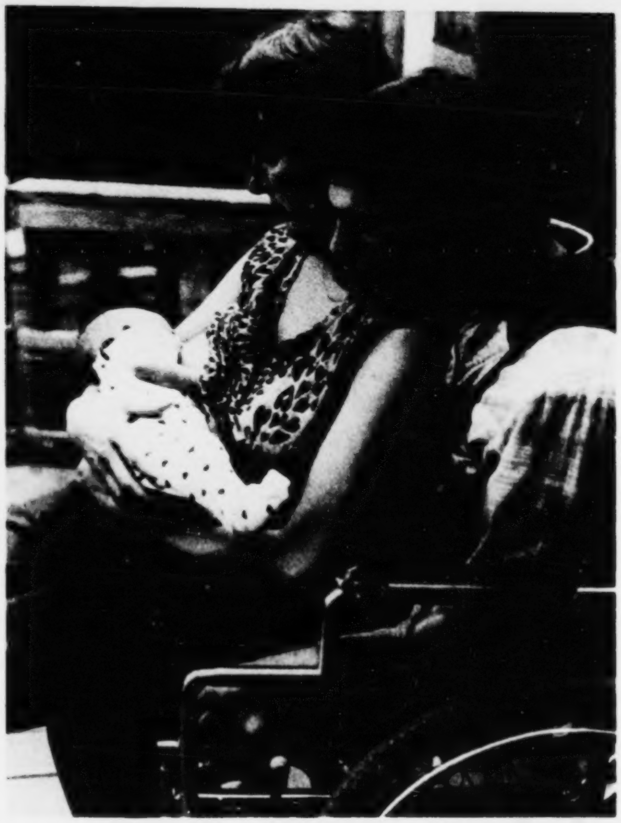
Drawing on past research and clinical work, and because of a critical community need, we are beginning to develop adaptive equipment for disabled parents under this year's NIDRR grant. Disabled parents' ingenious use of ordinary baby equipment directs our efforts. The exploration of equipment and facilitating of adaptive strategies is often blended with clinical work. To give a current example, a couple with a history of alcoholism and battering by the ablebodied husband has just had a baby. The mother has hemiplegia, and ordinarily walks with a cane, with difficulties balancing while walking and use of only one arm. Again there is a pattern of underfunctioning by the disabled mother, triggering anger and in this case physical abuse by the ablebodied father. A prompt attempt was made to maximize the mother's physical ability to function by providing an adapted crib, and a reclined stroller with good support for the mother so she could move the baby from room to room. The ability to do her own baby care would eliminate one element of her 'need' to remain in a battering relationship. Yet the requested efforts to increase the mother's practical functioning are not yet being incorporated. This is an indication, we believe, that more in-depth preliminary work needs to clarify the meaning of the pattern for these individuals, and to support their tolerance of a change in the balance of functioning between them. The connotation of the disability is addressed by the clinician being herself a disabled woman; further addressing of implications of disability may be pursued, eventually, by the introduction of videotapes of other disabled parents.

The core of the problem with assessing disabled parents seems to be lack of experience and perspective. One of the goals of our work is to give a sense of the wide spectrum of capability in parents with disabilities.

The assessment of parenting capability

In general, we have found that many professionals have difficulties in the assessment of disabled parents, with a tendency to be overly sanguine or avoidant, or the inverse, to be overly alarmist. The former may result in no supportive services when these are actually needed; the latter may result in a flood of superficial and uncoordinated services that undermines parental self-esteem or further disorganizes a multi-risk situation. One of the goals of our work is to begin to inform more realistic assessments, by giving a sense of the wide spectrum of capability in parents with disabilities.

This is based on our program's experience with parents who range from well-functioning mentors to those with different degrees of need for services. A



situation that often calls for our blend of infant mental health, family therapy and peer counseling interventions is when a disability has begun during or worsened during pregnancy or postnatally (such as postnatal exacerbation of multiple sclerosis). Depression and disorganization of the usual adaptations can interfere with the formation of the relationship with the infant. The most high-risk situations that we have dealt with have involved childhood history of weakened or failed infant/parent relationships (often involving poorly supported, depressed parents, early removal to multiple foster homes or institutions for the disabled), often involving sexual and/or physical abuse. Substance abuse in the disabled adult or partner, battering, isolation, poor current support systems, poverty, and cognitive limitations are often also common factors in multi-risk disabled parent families. In other words, these are parents familiar to the infant mental health program serving multi-risk families; they do, however, include the added dimension of parental disability.

The core of the problem with assessing disabled parents seems to be lack of experience and perspective. Many professionals are unfamiliar with how disabled people live independently in the community, how teaching independent living skills and adaptive equipment and home modifications assist in this, what kinds of support systems (including attendants) are used. Realizing the kind of resilience and problem-solving ingenuity already required to overcome the obstacles to independent living makes it easier to facilitate disabled parents' ability to apply their survival skills in the new area of parenting. Knowing more about well-functioning disabled adults makes it easier to separate disability issues from psychosocial and infant mental health issues.

I would like to explain how familiarity with the territory of disabled parenting is informing our assessments. First of all, both our research and clinical work suggest that an accurate assessment of disabled parents needs to look at areas of functioning where the parent is 'adaptively stressed', or stressed in terms of his or her disability, and to contrast, balance this with looking at areas where the parent's disability is less of a factor. For example, one of the parents is our Easter Seal study was extremely adaptively stressed during preparations for baths. She was not an individual who pre-planned or organized her baby care in such a way as to have on hand all that she needed for a bath, and she was a single mother without someone to fetch forgotten objects for her. This meant many trips back and forth retrieving things; trips required mobility. Prior to having the baby she had used Canadian crutches to support walking. She had grown up with considerable pressure to be ambulatory and to avoid the use of a wheelchair. When ambulatory disabled people have a baby they have to solve the problem of how to move the baby from place to place safely and maintain their balance. Some push their baby in a bassinet on wheels, some use a stroller with good support, but many use a wheelchair, either riding in it and carrying their baby or strapping theirr baby into the wheelchair (first perhaps in a car seat). This mother used a wheelchair but, apparently due to the connotation of wheelchairs for her, always resisted modifying her house to receive it. The result was confusing, interrupted and stressful interaction with her baby during preparations for baths. An assessment of this mother's capability focusing on these preoccupied, 'adaptively stressed' periods would not have captured the quality of her general relationship. During feeding and play it looked quite lovely and sensitive. One would have needed to look at the areas with and without adaptive stress in order to formulate interventions to both address problem areas and tap infant/parent relationship strengths.

Adequate equipment and facilitation or teaching of adaptive strategies are key in reducing 'adaptive stress'. For a severely disabled parent, the absence of these can mean that certain care is not feasible, therefore not observable for assessment! Providing an adapted frontpack can mean a mother can comfortably cuddle her baby for the first time. Providing a safe, contained and 'entertaining' changing area can transform a dangerous struggle during diapering into a workable situation. A fair and accurate assessment of parental capability and the potential of a parent/infant relationship cannot, in my opinion, be done prior to the provision of adaptive teaching and equipment.

In assessing a disabled parent where there has already been a prolonged separation between parent and baby, there seem to be some considerations unique to disabled parents. Our research has been documenting how the adaptive collaboration between parent and baby, when it occurs, develops gradually over time, apparently beginning during the first weeks of life. Disabled parents who care for others' children report that, with ongoing contact over time, they can teach them this 'cooperation' to an extent. Consider a situation of longterm removal into foster care, with limited visitation and no other contact with disabled adults for the baby. In such a case, an assessment of parenting ability of a severely disabled parent can be obfuscated by the lack of opportunity for the development of the baby's cooperation with care, or the gradual working out of the parent's adaptations. Physical care may be or appear to be impossible because there has not been an opportunity for the normal collaboration to evolve. This is complicated by a weakened relationship resulting in lack of motivation on the part of the baby; for instance, a toddler is not going to want to climb up a wheelchair into the lap of a mother when the tie to her is very attenuated.

> *We have found our videotapes of physically disabled parents, used with clinical sensitivity, can be powerful for the parents of disabled young children. They provide a window on the potential of both full and ordinary lives for physically disabled adults.*

In one assessment situation, after such a longterm removal, a toddler had an avoidant and aversive reaction to his severely disabled mother. I couldn't see an adequate explanation for this in the mother's behavior. The mother had never had an opportunity for past abuse that could account for the baby's present anxiety. He had a preference for any ablebodied person, even strangers, over his disabled mother. In his foster home he acted secure, calm and friendly. I noted his auditory sensitivity and wondered if he could be frightened of the noise of his mother's motorized wheelchair. I began experimenting with the mother being out of her wheelchair during his visits, and having people with whom he was already comfortable sit in and operate the chair. He acted upset and anxious when held in the wheelchair by these individuals (though this was gradually decreasing). He was willing to play (ball) with his mother for the first time from the outset of these floor visits. By the second such visit his previous (pervasive) anxiety had seemingly disappeared and he initiated (extensive) vocalizing, social play and 'en face' positioning with her. These had been absent before. By the third such visit he was, for the first time, willing to be fed and touched by her, laughed at tickling physical contact, and started playing with the footrest of the wheelchair. During the last two visits the only moment of clear anxiety occurred while his mother was transferred (separated) from the wheelchair down to the floor. This compelling work would need to be continued, consolidating the relationship to the 'floor mom', while simultaneously desensitizing him to the wheelchair. One could then, I believe, move on to working on the relationship with 'mom in wheelchair'. Only at that point, in my opinion, could you do an assessment of the parent/baby relationship that could begin to estimate its potential.

It was possible to sort out the preceding situation because it was so out of tune with the norm of disabled parent/baby interaction. As documented in our videotapes and cases, it is usual for the children of disabled parents to consider their parents' disability equipment, wheelchairs, reachers, etc., an ordinary part of their environment. A 'reacher' is twirled like a baton, a wheelchair is usually a wonderfully entertaining and useful object: a convenient climbing structure or favored place to pull to stand, its footrest a riding toy just the right level for a toddler. For a young child of a parent in a wheelchair, this equipment does not seem to carry a negative connotation. For instance, a five year old told her extremely competent and independent paraplegic mother: 'When I grow up I want to be a mommy, and have a van and a blue wheelchair.' 'Oh, you won't need *that*, said her concerned mother. 'But I *like* blue', the child insisted. I think we have much to learn from the children of disabled parents; from their viewpoint the definition of parenthood can often include disability in a matter-of-fact way.

Implications for parents with disabled babies

Under our NIDRR projects we have been increasingly focusing on the import of our work with disabled parents for parents with disabled children, and for the professionals with whom they work. We blend services to both populations as part of the underlying effort to bridge the parent and disabled communities. We have found that our videotapes of physically disabled parents, used with clinical sensitivity, can be powerful for the parents of disabled babies and young children. They provide a window on the potential of both full and ordinary lives for physically disabled adults. Their content is the concrete stuff of parenting babies; this seems to make the tapes both accessible and resonant for the parents of physically disabled babies.

For the clinician the blend of perspectives is profound. At one point I am videotaping a well-functioning mother with arthrogryposis, carrying her baby in a wheelchair in a front pack, as she transfers from bus to train on her way to work. At another point I'm nurturing the relationship of a grieving ablebodied parent and a baby with arthrogryposis, and, when this can be tolerated, providing videotape images of future possibilities. And at another point I'm working with a multi-risk pregnant woman with arthrogryposis, whose ambivalent disengagement from her pregnancy is deeply linked to her sense that her mother conveyed active sexuality and parenthood as unspeakable for her—not to be *part* of her future. The depression this pregnant woman feels is surfacing memories of her mother's unsupported grief at her baby's disability, and memories of recurrent separations during her mother's subsequent hospitalizations for severe depression.

In conclusion, I would like to encourage other professionals who work with families and physically disabled babies to broaden their experience to such a life-cycle perspective. If we are to help families with the formation of 'new dreams', a sense of future for their disabled babies, I think we need to nurture our own abilities to project beyond infancy. It may help to sustain our efforts if we remember that supporting families with disabled babies, seeding possibilities, will mean fewer multi-risk disabled parents in the future.

Bibliography

Anthony, E. 1970. The Mutative Impact of Serious Mental and Physical Illness in a Parent on Family Life. In *The Child in his Family, I*, eds. E. Anthony & C. Koupernick, New York: John Wiley & Sons.

Buck, F. 1980. The Influence of Parental Disability on Children: An Exploratory Investigation of the Adult Children of Spinal-cord Injured Fathers. Unpublished doctoral dissertation, University of Arizona.

Buck, F. & Hohemann, G. 1983. Parental Disability & Children's Adjustment. In *Annual Review Of Rehabilitation. III* eds. E.L. Pan, T.E. Backer, and C.L. Vash. New York: Springer-Verlag.

Bunder, L.T. 1979. *Deaf Parents—Hearing Children.* Washington, D.C.: Registry of Interpreters for the Deaf.

Gleidman, J., and Roth, W. 1980. *The Unexpected Minority.* New York: Harcourt Brace Jovanovich.

Hale, G. (ed.) 1979. The Disabled Parent. In *The Source Book for the Disabled*, New York & London: Paddington Press Ltd.

Kirshbaum, M., and Rinne, G. 1985. The Disabled Parent. In *Maternity Nursing: Dimensions of Change*, eds. M. Auvenshine and M. Enriquez. Monterey: Wadsworth.

Lifchez, R., and Winslow, B. 1982. *Design for Independent Living: The Environment and Physically Disabled People.* Berkeley: University of California Press.

Meadow, K; Greenberg, M.; and Erring, C. 1983. Attachment Behavior of Deaf Children with Deaf Parents. J. Am. Acad. Child Psych. 22 (1):23-28.

Olgas, M. 1974. The Relationship Between Parents' Health Status and Body-image of their Children. Nurs. Research. 23:319-324.

Parks, S. 1984. *HELP: When the Parent is Handicapped.* Palo Alto: VORT Corporation.

Rutter, M. 1966. *Children of Sick Parents: An Environmental and Psychiatric Study.* London: Oxford University Press.

Thurman, S.K. (ed.). 1985. *Children of Handicapped Parents: Research and Clinical Perspectives.* London: Academic Press.

Turnbull, A.P. and H.R. Turnbull. 1985. Stepping Back from Early Intervention: An Ethical Perspective In *Journal of the Division for Early Childhood.* 10:2:106-117.

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New Journals

Infants and Young Children: An Interdisciplinary Journal of Special Care Practice is edited by James A. Blackman, M.D., of the University of Iowa College of Medicine. Published quarterly, the journal is designed to provide a link from theory to practice in early intervention for children 0-3; **Infants and Young Children** includes peer-reviewed articles, essays, and special sections on professional education, technology and exemplary practice. Disciplines represented on the editorial board include administration, dentistry, education, neonatology, neurology, nursing, nutrition, occupational therapy, parent support, pediatrics, physical therapy, psychology, public health, public policy, social work, and speech and hearing. Free copies of the initial issue are available by calling Aspen Publishers, Inc. at 1-800-638-8437.

The **American Journal of Community Psychology (AJCP),** sponsored by Division 27 of the American Psychological Association, encourages submission of articles that examine issues with direct implication for social policies, including experimental studies, field and evaluation research, intervention studies, and cross-cultural studies that assess the assumptions, implementation and outcomes of social policies; theoretical articles and reviews that examine relations among research, practice, policies and the policy process; and descriptive articles that trace the development and implementation of policy, particularly insofar as the actual or potential contributions of psychology are highlighted.

Manuscripts may be submitted to Julian Rappaport, AJCP Editor Elect, Department of Psychology, University of Illinois, 603 E. Daniel St., Champaign, IL 61820 or to Deborah Phillips, associate editor for social policy, Department of Psychology, University of Virginia, Charlottesville, VA 22903, tel: (804) 924-0668.

Development and Psychopathology, to be published by Cambridge University Press beginning in 1989, will be an international multidisciplinary journal devoted to the publication of original empirical, theoretical and review papers which address the interrelationship of normal and pathological development in adults and children. The journal is intended to serve and integrate the emerging field of developmental psychopathology, which strives to understand patterns of adaptation and maladaptation throughout the lifespan. Manuscripts should be submitted in triplicate to Dante Cicchetti, Editor, Mt. Hope Family Center, University of Rochester, 187 Edinburgh Street, Rochester, NY 14608, tel: (716) 275-3384.

Erratum

In the article "Preparing Pediatric Residents for the Primary Care of Children with Chronic Illness and Their Families: The Chronic Illness Teaching Program," which appeared in February, 1988, the statement at the bottom of page 9 should be "The first group to complete the full three-year sequence will graduate during 1988."

Parent Education and Infant Monitoring: A Model Demonstration

by
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Early intervention services to young children with disabilities or at risk of developmental delay can fulfill their promise only if children and families who can benefit from services are identified in a timely way and connected to appropriate providers. This article describes a model demonstration program, funded by the U.S. Department of Education's Handicapped Children's Early Intervention Program, that was designed to: 1) demonstrate the effectiveness of monitoring the at-risk infant population for identification and subsequent intervention if needed; 2) demonstrate the effectiveness of teaching parents to monitor and facilitate their infant's development; 3) demonstrate the effectiveness of a parent-to-parent model to provide these services.

Demonstration programs represent a type of research that is critical to improved practice in any human services area, and nowhere more important than in work with infants, toddlers and their families. The Parent Education and Monitoring Program addressed a service system need for more accurate, earlier, and cost effective approaches to identify infants with developmental problems and to connect them to appropriate services through an approach grounded in the work of both academic researchers and interventionists. The project's focus on parents reflected a mixture of conceptual, philosophical and practical concerns.

One issue that currently frustrates interventionists and program planners alike is the fact that while infants having severe handicaps are usually recognized during the first weeks of life, (Hayden & Beck, 1982) effective strategies for identifying infants with mild or moderate handicapping conditions have proven to be elusive. Interventionists and researchers continue to search for prediction models which will help to identify these infants (Field, 1981). At this time, models which incorporate variables from an infant's biological, behavioral, and environmental domains seem to present the best potential for prediction (Sameroff, 1982). Nevertheless, these models are still being derived, and as such, the data base created by them is still undergoing refinement.

It has recently been suggested that screening and intervention procedures be concentrated on populations of infants at an increased risk for developing delays because of medical or environmental factors. This subsample of infants would include those born with medical complications which required their placement in neonatal intensive care units, those born into families living in poverty, and those born to teenage mothers. It has been estimated that up to 30 percent of these infants considered at risk subsequently develop delays (Scott & Masi, 1979). Establishing and maintaining contact with families having such infants is no easy task. It is usually more difficult to connect these families to appropriate services if their infants experience developmental delays.

The Parent Education and Monitoring Program, then, set itself a double challenge: to find a method to improve early identification of infants experiencing developmental delays and to do so in a population where the very factors that were likely to contribute to delay were also likelty to render traditional screening and assessment services ineffective.

Program description

When Virginia Commonwealth University was awarded a three-year model demonstration grant in 1984, the city of Richmond, Virginia had a population of approximately 200,000 people and six separate agencies providing a variety of services to at-risk or delayed infants. Each of these agencies was individually administered and had a separate funding structure. Though approximately 100 handicapped infants under two years of age were receiving services, it has been estimated that at least 203 were eligible for services during 1984-85 (Richmond Mental Retardation Community Services Board). In 1984, neither the State of Virginia nor the City of Richmond had a comprehensive monitoring or child find system in operation for infants 0-2.

The primary consumers of the Parent Education and Monitoring Program were to be parents of infants (age 0-24 months) considered to be at risk for developmental delay because of medical or environmental factors. An upper age limit of 24 months was chosen for two reasons. First, the state and local education agencies in Virginia provided public school services for delayed young children from the age of two. Second, it has been documented that by 24 months developmental and environmental assessments are valid predictors of subsequent child development (Bakeman & Brown, 1980; Bee, Barnard, Eyres, Gray, Hammond, Spietz, Snyder & Clark, 1982). Eligible participants included parents with infants who had spent time in a neonatal intensive care unit and parents who were 17 years and younger (in 1984, 1,133 of the 3,409 deliveries in the City of Richmond were to teenage mothers). Other parents, including those with infants identified as handicapped, or those having handicapping conditions themselves, were allowed to participate through either self or agency referral. Participation in the program was voluntary and at no cost to parents. Parents received initial contacts about the program while in city hospitals after delivery of their infant.

Program staff consisted of 3.5 full-time equivalent parent educators who had either social work or special education backgrounds, a part-time director, and a part-time secretary. Two of the professional staff were also parents of children with handicaps.

The case vignettes and aggregated data from the program, which follow, suggest the flavor of our work as well as its impact.

Monitoring

"By the time she was one, I knew there was something wrong, but, the doctors wouldn't listen."

"I needed to learn a lot about a baby and what he needs, but I didn't know who would tell me."

"(The questionnaire) helped me learn how he should grow, eat, and how he is supposed to do his moving and other good things."

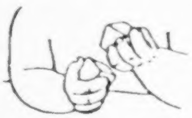
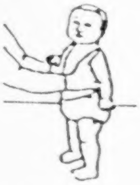
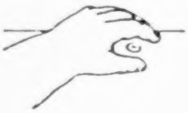
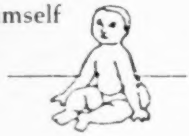
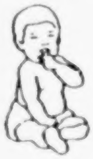
The major goal of developmental screening is to reduce the time that elapses before intervention begins. However, wide ranges and variations in normal development and behavior during the early years make meaningful screening difficult. In an effort to alleviate some of the inherent difficulties with screening, some investigators have involved parents in the screening process, often using a parent-completed screening device (Bricker & Littman, 1983; Field, Hallock, Dempsey & Shuman 1978; Frankenburg, Van Doornick, Liddele & Dick, 1976; Knobloch, Stevens, Malone, Ellison & Rosenberg, 1979; Harper & Richman, 1979; Bates, Freeland & Lounsbury, 1979; Thompson, Curry & Yancy, 1979). In addition to the most obvious identification advantage which this procedure offers, the developmental information in parent-completed developmental checklists can also have potential intervention effects (Bricker & Littman, 1983; Swanson, 1979). The Parent Education and Monitoring Program decided to test this strategy with its participants.

Tia and Iris. **Tia was 16 when her daughter Iris was born. She had dropped out of school and supported herself through Aid to Dependent Children payments, WIC and food stamps. Tia agreed to participate in the parent project while in the hospital for Iris' birth. A parent educator from the project visited Tia and Iris within two weeks of their return home. During the first visit, Margie (the parent educator) explained the program to Tia and completed initial assessments on Tia's needs, perceptions, and interactions with Iris. During the next two months, Margie and Tia became friends as Margie continued to collect information on both Tia's and Iris' needs. Margie also brought Tia some toys for Iris and any information Tia requested. During one of these visits, Tia helped to administer and record Iris' behaviors on a developmental assessment. After the first three months, Margie began to visit Tia and Iris at three-month intervals. Margie continued to help Tia identify her needs and assisted in the coordination and location of any new information needed. Tia also filled out a developmental questionnaire (see Table I) on Iris every three months. Margie and Tia then went through the questionnaire together as a reliability check. Tia was 100 percent reliable in her ability to monitor Iris' developmental status, and it was documented that Iris was well within the normal developmental range expected for her age. Tia claimed that the picture questionnaire and developmental toys had given her lots of ideas on ways to play with Iris.**

Lois and Michael. **The monitoring system provided a different focus of services for nineteen-year-old Lois. Lois was mentally retarded and lived with her mother, brother, and infant son, Michael, in public housing. She, like Tia, supported herself and Michael through ADC, WIC and food stamps. She and Michael participated in the same home visit schedule as Tia. However, at six months of age, Michael failed the developmental questionnaire as reported by Lois, and Allison, the parent educator. In particular, he was behind in his motor development. He was not turning over or prop sitting, and he was arching when on his back. Lois was asked if we could call her pediatrician (a standard project procedure) and schedule a repeat of the entry level assessments conducted on Michael. Lois readily agreed to this, since she said she wanted Michael to "do things and she was scared she didn't know what to do." Since transportation was a major problem with most of the projects parents (it would have taken three bus transfers for Lois to get to the project's office), Allison picked up Lois and Michael for the assessments in the program office. As usual, Lois helped to administer the assessments. Michael's scores were in the abnormal range on the Bayley Scales of Infant Development and Battelle Developmental Inventory. These results were given to Michael's pediatrician, and a referral was made to the child development clinic. Allison went along on the clinic visit, during which Michael was given a neurological and developmental exam. Michael was diagnosed by the developmental pediatrician as having a developmental delay without evidence of neurological damage. In other words, Michael's motor problems may have been a result of environmental deprivation. The clinic team recommended an intervention program which would focus on Lois and her caretaking skills. Allison began to visit Lois and Michael weekly. During these visits she brought toys, played with Michael, and reinforced appropriate behaviors by Lois. She always left one specific activity for Lois and Michael to do together. These sessions proved to be rewarding for everyone, especially Lois. At Michael's follow-up assessment at 12 months, his scores had improved to the low normal range. He subsequently passed his 15-month developmental questionnaire and Allison continued to see Lois and Michael monthly.**

Table 1

Questionnaire 2 5-8 months

		Yes	Some-times	Not Yet
1. Does your baby pick up two things (such as toys or cookies) and hold one in each hand at the same time? Check NO if you have never seen him do this?		☐	☐	☐
2. When you hold your baby under his arms, can he bear some weight on his legs? Check YES only if he tries to stand on his feet and support some of his own weight.		☐	☐	☐
3. Does your baby pick up small objects with raisins or pieces of food with his hand using a raking or grabbing motion as in the picture below?		☐	☐	☐
4. Without being propped by pillows, a chair or wall, can your child sit by himself for 60 seconds?		☐	☐	☐
5. Does your baby feed himself a cookie or cracker?		☐	☐	☐

Monitoring results

The developmental questionnaire proved to be an effective screening tool with more than 100 children aged three months through 24 months. The majority of these infants were referred to our program shortly after birth on the basis of environmental risk factors. The mothers of these infants, as a group, were undereducated (most had not finished high school), and young (mean age, 17), lived in poverty, and lived with a high level of stress and a lack of support networks as reported by the program evaluation instruments. They also scored very low on the home environmental scale and parent child interaction scale.

It is noteworthy that parents' ratings of their infants' development according to the program questionnaire were in complete agreement with subsequent ratings by the parent educators 88 percent of the time—a rate of reliability that is impressive even for ratings by two professionals. A major factor contributing to parents' skills in observing their 3 to 24 month old children may be that the parents in our program had assisted in the administration of developmental assessments when their infants were six weeks old. Perhaps the most important result of the project's monitoring system was the identification and facilitation of referral of 14 infants into intervention programs.

Resource management

"The program is helping to get my daughter in touch with the right physicians she needs and in the right hospitals and public schools."

"The most helpful part was when I asked one of the staff if I could go back to school and have a job and she said yes, she would help me pick a good school I can go to. She said she thinks I can make it."

"It's hard to find what my baby needs in this city."

While searching for appropriate services for their handicapped or at-risk infant, parents must take three steps to gain access to what they and their children need. First, parents need to identify what their needs are. Second, they need to translate their needs into the proper service "label." Third, they need to contact the appropriate agency that delivers that specific service

(Rubin & Quinn-Curran, 1983). The first two steps, in particular, rely on the quality and degree of information given to parents. Improving the process of information sharing was an important part of the Parent Education and Monitoring Program.

Becky and Timmy. **Four-month-old Timmy was referred to the parent program by the outpatient therapy clinic at the Medical College of Virginia. Becky, his mother, was 17 years old at the time of Timmy's birth. Timmy and Becky lived with Becky's husband and mother. Timmy spent the first eight weeks of his life in a neonatal intensive care unit. While there, he was treated for prematurity (thirty-three weeks gestational age), apnea, breathing difficulty, lack of suck reflex, and poor weight gain. At discharge, he was referred to the outpatient therapy clinic for weekly occupational therapy sessions. He was being fed through a nasogastric tube which required daily maintenance, and he was receiving high doses of medicine for bronchial pulmonary dysplasia. A visiting nurse helped stabilize the medical management of Timmy for the first few weeks at home, but everything soon became too much for Becky. She began missing O.T. appointments and the NICU follow-up clinic.**

Kate, the parent educator, began weekly visits with Timmy after he had been home five weeks. Kate's main focus with Becky was to provide her with information about resources. Becky and Timmy were assessed on the parent program instruments, and regular meetings were scheduled by Kate with the other professionals serving Timmy. On the parent resource survey, (see Table 2), Becky initially indicated she was receiving multiple services. Her main need was for information on occupational therapy and home nursing. This seemed crucial in light of Timmy's immediate health needs and service delivery structure. Kate's first priority was to help Becky understand the need for Timmy's occupational therapy and help re-establish her visits with the occupational therapist. Information was also given to Becky on community resources such as public transportation and intervention programs. After six months in the program, Becky and Timmy were still being seen by Kate, though visits became bimonthly. Becky was taking Timmy to O.T. and follow-up clinic for scheduled visits, and she used the city bus system. She also could feed Timmy orally and had established a facilitative interactive pattern with Timmy that was reinforced by Kate. Timmy weighed 14 pounds at 12 months corrected age. He was delayed motorically though he was starting to pull to stand and cruise around furniture. Becky reported that her life had become "manageable."

Sandra and Ebony. **When Ebony was 5 months old, Sandra suspected something was wrong because Ebony was not able to stand. Sandra was referred to the parent program by her sister, Elisa. Sandra had been seeing her pediatrician regularly and had voiced concerns over Ebony's delayed development. Sandra was assured by the pediatrician that everything was "fine." After Sandra referred to the parent program, a parent educator talked with Sandra and did an assessment on Ebony. Ebony was found to be about 50 percent delayed in most areas of development. The Parent Program helped Ebony find a developmental pediatrician who referred Ebony to a local intervention program. She began receiving early intervention services. A parent educator from the Parent Program visited Ebony every other month to be sure that Sandra and Ebony were receiving the services that were needed.**

Resource management results

A resource assessment has provided a system for tracking and managing the needs of approximately 200 families in Richmond. The average number of community resources needed by a family was four. During the initial visits by parent educators, parents seemed to have difficulty identifying their specific needs. By the three- and six-month visit they had become more aware of the service system, and by 12 months the parents were demonstrating a greater level of independence. The information provided by the program had enabled parents to access the city transportation system, social services, WIC and food stamps, the adult learning center (for G.E.D.'s), and child care. The most exciting aspect of this service had been the growing independence and assertiveness demonstrated by parents as they learned to use the community resource system.

Conclusion

The parents who were enrolled in the demonstration project represent a population sample which was undereducated, under age, and living in poverty. These factors have been identified as placing a child at risk for later developmental delays. An educational program for parents focused on early detection of developmental delays in children seemed to be appropriate for this group, and the high percentage of the total sample of infants subsequently referred to intervention services demonstrated the importance of a tracking and identification system for infants displaying risk factors.

The Parent Education and Monitoring Project demonstrated the effectiveness of monitoring the development of an at-risk population of infants for identification purposes. Both the developmental assessments conducted during project intake and the subsequent developmental questionnaire proved to be effective child-find mechanisms. Of the 14 infants identified for an in-depth assessment, 7 were identified through the questionnaire system, while the others scored low on the intake assessments before beginning the questionnaire system. That all 14 were subsequently referred to intervention reflected an extremely accurate screening. It is surprising, and somewhat distressing, that these infants were *not* identified as having delays by traditional means, such as through the health care community. One can only speculate as to the age at which they may have been referred for appropriate intervention if they had not been identified through the monitoring project.

Of additional interest to this and other screening programs was the rate of false negatives, or the under-identification of infants demonstrating delays. Although data suggest that the Revised Denver Developmental Screening Test may have a higher than acceptable false negative identification rate (Meisels, 1985), we did not have this experience. The professional judgment of parent educators seemed to provide an added dimension of reliability. An additional control for identification purposes was the three developmental assessments (at entry, one and two years) the infants received during their participation.

The picture questionnaire system seemed to be a viable vehicle for both parent education and infant monitoring. The parents successfully completed the questionnaire independently and with a high rate of interrater reliability. The parents themselves identified developmental problems with the questionnaire before their observations were verified by the parent educator.

An important factor which may have contributed to the parents' ability to use the questionnaire accurately was their participation in the initial intake assessment on their infant (i.e., Bayley Scales and Battelle Developmental Inventory at initial entry to program). Studies have suggested the benefits to both parents and children when the parent observes an assessment of their child. In addition, the subsequent assessment process for those infants identified as needing further evaluation seemed less stressful for their parents, who were familiar with assessment procedures.

The cost effectiveness of these tracking and screening procedures must be highlighted. A total staff of three full-time bachelor-level professionals managed the entire case load of the program. Since this was a model demonstration program, additional time was spent on evaluation and community training. Since families were seen a maximum of once a month, the staff accommodated a large number of individual cases. Home visits lasted approximately one hour, though travel time and missed appointments brought the average time for a home visit to three hours. The overall attrition rate of 25 percent was relatively low for inner city families. Using an hourly wage of $7.00 to $8.50 for the parent educators, we envision approximately 60 infants a year being served by one full-time parent educator (salary $16,025-$19,000).

Interagency cooperation was a major goal of the demonstration project, since all of our families used health care providers, and most received Aid to Dependent Children, WIC and Medicaid. Since the project also collaborated with numerous intervention programs, community agencies, and extended family members, a major goal was the facilitation of communication and joint intervention efforts for the participating infants and their parents. The project's thirty-five member advisory board was instrumental in developing an interagency task force for infant intervention in Richmond which met monthly to identify and address issues such as: the adoption of a common case management policy by all six intervention programs; a common evaluation plan for six regional infant intervention programs; a joint workshop to address transition issues between infants and preschool programs; cooperative referral policies for teenage parents; the sponsorship of parent education groups by project staff within outside agencies such as the Richmond Public Library System, two city infant intervention programs, and the Richmond Public School Infant Program; and joint training activities sponsored by the project on such topics as family-focused intervention, program evaluation, parent-child interaction measures, and hard-to-reach parents. These combined efforts culminated with the award of a state developmental disabilities grant to demonstrate a model interagency service system for infant tracking and intervention services in Richmond. The model, the Parent Infant Intervention Project, is comprised of the four city agencies serving infants and families (Education, Health, Mental Health & Mental Retardation and Social Services) and the six existing early intervention programs. The model is exploring options for family-focused early intervention services which will minimize the current cost requirement for services. A rigorous training component is in place within the model to encourage professional development on a number of levels among the agencies and programs serving infants and families.

A major component of the Parent Education and Monitoring Program, Parent to Parent of Greater Richmond, received state funding during the last eighteen months of the project to establish a separate financial structure and advisory board. Parent to Parent is currently providing technical assistance to programs and agencies throughout Virginia that wish to begin a parent to parent support network within their community.

One additional outcome of the project has been an increase in the total number of infants receiving intervention services in Richmond. During 1986, approximately 225 infants were enrolled in intervention, while the total number of infants born in Richmond remained stable (3,480). This increase brought the numbers of infants enrolled in intervention to 3 percent of the total infant population.

The success of the Parent Education and Monitoring Program can be directly attributed to its focus on families and to its non-intrusive, cost effective service model. The approach and service model are both in the spirit of P.L. 99-457. Components validated through the Parent Education and Monitoring Program, that may be useful to other jurisdictions' programs, would include the developmental screening and monitoring system using parent-completed questionnaires, its tracking and case management system for at-risk infants and their families, and the interagency process and policies on infant intervention services which were developed.

References

Bakeman, R. & Brown J. (1980). Early interaction: Consequences for social and mental development at three years. *Child Development, 51,* 437-447.

Bates, J., Freeland, C., & Lounsbury, M. (1979). Measurement of infant difficultiness. *Child Development, 50,* 794-803.

Bee, H., Barnard, K., Eyres, S., Gray, C., Hammond, M., Spietz, C., & Clark, B. (1982). Prediction of IQ and language skill from prenatal status, child performance, family characteristics, and mother-infant interaction. *Child Development, 53,* 1134-1156.

Bricker, D. & Littman, D. (1983). *Parental monitoring of infant development.* Paper presented at the Banff International Conference, Alberta, Canada.

Field, T. (1981). Intervention for high risk infants and their parents. *Educational Evaluation and Policy Analysis, 3,* 69-78.

Field, T., Hallock, N., Dempsey, J., & Shuman, H. (1978). Mother's assessment of term and pre-term infants with respiratory distress syndrome: Reliability and predictive validity. *Child Psychiatry and Human Development, 2,* 75-85.

Frankenburg, W., Van Doornick, W., Liddele, T., & Dick, N. (1976). The Denver prescreening developmental questionnaire (P.D.Q.). *Pediatrics, 57,* 744-753.

Harper, D., & Richman, L. (1979). Preschool screening for behavior problems. *Psychology in the Schools, 16,* 38-42.

Hayden, A. & Beck, G. (1982). The epidemiology of high-risk infants. In C. Ramey and P. Trohanis (Eds.), *Finding and educating high-risk and handicapped infants.* Baltimore, MD: University Park Press.

Knobloch, H., Stevens, F., Malone, A., Ellison, P., & Rosenberg, H. (1979). The validity of parental reporting of infant development. *Pediatrics, 63,* 873-878.

Meisels, S. (1985). Prediction, prevention and developmental screening. In H. Stevenson & A. Siegel (Eds.), *Child Development Research and Social Policy (Vol. 1).* Chicago: University of Chicago Press.

Rubin, S., & Quinn-Curren, N. (1983). Lost, then found: Parents' journey through the community service maze. In M. Seligman (Ed.), *The family with a handicapped child: Understanding and treatment.* New York: Grune & Stratton.

Sameroff, A. (1982). The environmental context of developmental disabilities. In D. Bricker (Ed.), *Intervention with handicapped and at-risk infants: Research to application.* Baltimore: University Park Press.

Scott, K. & Masi, W. (1979). The outcome from the utility of registers of risk. In T. Field, A. Sostek, S. Goldberg, and H. Shuman (Eds.), *Infants born at risk.* Jamaica, N.Y.: Spectrum Publications.

Swanson, J. (1979). Principles of infant assessment. In B. Darby and M. May (Eds.), *Infant assessment: Issues and applications.* Seattle: Westar.

Thompson, R., Curry, J., & Yancy, W. (1979). Utility of parents' behavior checklist ratings with developmentally disabled children. *Journal of Pediatric Psychology, 4,* 19028.

Call for Papers

The **Pre and Perinatal Psychology Association of North America** invites participation in its fourth international congress, to be held August 3-6, 1989 in Amherst, Massachusetts. Proposals for debates, symposia, papers, experiential presentations, and films are invited on topics including pre and perinatal stress, perinatal consciousness, pre and perinatal psychology and bioethics and cross cultural perspectives, among others. **Abstracts must be postmarked by August 31, 1988.** For guidelines contact Rima E. Laibow, M.D., Program Chair, 13 Summit Terrace, Dobbs' Ferry, NY 10522.

The Program Committee of the **Society for Research in Child Development** invites submissions of posters, papers, symposia, conversation hours and discussion-debate sessions for the biennial meeting to be held in Kansas City, Missouri, April 27-30, 1989. Review panels have been constituted in the following subject areas, among others: social and emotional processes in infancy; perception, cognition and communication in infancy; sensory, perceptual and motor processes; infants and children at risk; atypical development; developmental correlates of gender and ethnic group; and child development research and social policy. **Submissions must be received no later than Tuesday, September 6.** For submission guidelines, consult the Spring, 1988 *SRCD Newsletter* or write to Aletha Huston and John Wright, Co-Chairs, SRCD Program Committee, Department of Human Development, University of Kansas, Lawrence, KS 66045-2133.

ASPO/Lamaze seeks scientifc posters, research, and audiovisual materials for presentation at its annual conference, to be held October 21-22, 1988 in San Francisco, California on the theme, "Birth: Exploring New Frontiers." **Scientific abstracts must be received by August 31 and audiovisuals by September 15.** For guidelines contact Barbara Sienkiewicz, c/o ASPO/Lamaze, 1840 Wilson Boulevard, Suite 204, Arlington, VA 22201, tel: 1-800-368-4404 or (703) 524-7802.

The **Ninth Annual Conference of the American Council on Rural Special Education (ACRES),** which will be held March 6-8, 1989 in Fort Lauderdale, Florida solicits proposals for presentations concerning technology, infancy, personnel preparation, cross-cultural issues, and parent/professional concerns, among others. Proposals for a teacher institute and a parent institute on March 4 and 5 are also invited. **The deadline for receipt of abstracts in September 15, 1988.** For further information contact ACRES Symposium, Miller Hall 359, Western Washington University, Bellingham, WA 98225, tel: (206) 676-3576.

Volunteer Research and Action: Mothers in the Workplace

by

James T. Bond, Director
NCJW Center for the Child

The National Council of Jewish Women is a private voluntary organization with 100,000 members organized into more than 150 local affiliates nationwide. Since its founding in 1893, NCJW has always placed high priority on advocacy and community service for children and families at risk. Five years ago, the members of NCJW voted to establish a semi-autonomous research institute—the NCJW Center for the Child—to conduct research on child and family issues in the United States.

NCJW Center for the Child

The NCJW Center for the Child became operational in the spring of 1986 with the initiation of its first project—*Mothers in the Workplace*—a national study of the special needs of families in which mothers with young children work. In the first part of the study, more than 2,000 employers in 100 communities were surveyed to obtain information about workplace policies, practices, and fringe benefits of particular concern to working parents. In the second part of the study, interviews were conducted with 2,600 working women from the same communities during the third trimester of their pregnancies and again at 4 to 7 months after childbirth. Research findings are being released in a series of reports as data are analyzed.

The *Mothers in the Workplace* project is unusual not only in its scope, but also in its methods. Although the project was developed and managed by professional research staff of Center for the Child, volunteer members of NCJW affiliates around the country carried out all sampling and data collection in the field. Moreover, NCJW volunteers have also taken responsibility for disseminating research findings in their own communities and for putting these findings into action at the local, state and national levels.

Models for volunteer research and action

Involving "ordinary citizens" in the research process as investigators, not merely as subjects or informants, is still a fairly novel idea to professional researchers, funding agencies, and the "citizens" themselves. Nonetheless, NCJW's own organizational history offers several examples, ranging from loosely organized "fact finding" initiatives to more systematic survey research. The most ambitious of these projects was undertaken in 1970 by NCJW volunteers who investigated the supply and quality of child care services available to working parents in 77 communities around the country. The book resulting from that study—*Windows on Day Care* (M.D. Keyserling, 1972)—was among the first reports to draw the attention of policy makers to growing unmet needs for affordable, high quality day care in the United States. The project also served to educate and motivate hundreds of NCJW volunteers to address local child care issues through advocacy and community service.

In developing the *Mothers in the Workplace* project, Center for the Child staff picked up this same thread fifteen years later, hoping to refine, and possibly institutionalize, a model for volunteer research and action that could be used to address a broad range of issues affecting children and families in the United States. Indeed, as data collection for *Mothers in the Workplace* was winding down in the fall of 1987, the Center mounted a second volunteer-staffed project—*Children as Witnesses*—which is investigating the criminal prosecution of child sexual abuse cases in 11 jurisdictions around the country. Still other variations of the model are on the drawing boards and will be put to the test in coming months and years. These experimental models for volunteer research and action give particular emphasis to the potential of the research experience as a means for citizen education and of research findings as a basis for citizen action, while also maintaining standards of research to ensure contributions to scientific knowledge.

Potential for action

Voluntary organizations with broad membership bases and strong organizational presence at the grass roots level have enormous potential as vehicles for putting the findings of research into action, if not directly through programming, then indirectly through advocacy of responsive private and public policy.

Over 1,000 volunteer researchers from NCJW, as well as other organizations, in 100 communities participated in one facet or another of the *Mothers in the Workplace* project. Many were working mothers with young children themselves; others were grandmothers whose daughters are juggling work and family responsibilities. Their experiences interviewing employers and working women of diverse backgrounds were eye-opening and unsettling. They learned firsthand about the startling number of employers who do not offer group health insurance coverage to some or all of their employees or who do not provide any job-guaranteed leave for maternity. They witnessed the difficulties faced by single mothers who want to return to work after childbirth but simply cannot afford to do so given the costs of child care and lack of benefits on the job. They discovered, or rediscovered, how stressful it is for new mothers to return to work before they or their infant are ready and without adequate support from family or community.

Educated *and* motivated by their experience, volunteer researchers were anxious to share their findings with working parents, employers, public policy makers, and the general public. To date, their efforts to disseminate national and local findings from the study have generated several hundred articles, including numerous feature stories, in the local and regional press.

In addition to gaining extensive press coverage, many local affiliates of NCJW have also taken substantive action in their communities and states. In some

communities, NCJW volunteers have sponsored community forums that draw together business and civic leaders, unions, voluntary organizations, child care professionals, and others to address the needs of working parents in their communities. Using findings from the study and firsthand knowledge of the issues, several NCJW affiliates have taken leadership roles in their states as advocates for legislation that would improve and increase the availability of medical and parental leave benefits in the workplace.

Capitalizing on the momentum generated by *Mothers in the Workplace*, the larger organization recently mounted a national program of public education, advocacy, and community service focused on the child care needs of working parents. With the development of this program, what was initially a research project of the Center for the Child has become an action initiative of NCJW—an initiative that has begun to stimulate the formation of local coalitions with other voluntary organizations and associations to address child care and other work-family issues.

The Center's role

The role of NCJW's Center for the Child in relation to the larger organization and the field is still evolving. In addition to their work with volunteer researchers, Center staff are currently conducting studies of child abuse prevention and early childhood education that do not involve volunteers and do not reflect the specific agenda of the larger organization. However, its special relationship to NCJW and its access to volunteer resources is clearly what makes the Center for the Child unusual, if not unique, among the many research organizations concerned with child and family issues. And developing the full potential of this relationship remains at the top of the Center's agenda.

Reports of findings from Mothers in the Workplace *are available free of charge from the NCJW Center for the Child, 53 West 23rd Street, New York, New York 10010.*

Publications

Within Our Reach: Breaking the Cycle of Disadvantage—Lisbeth B. Schorr, with Daniel Schorr (New York: Anchor Press, Doubleday, 1988) $19.95.

In the last two decades, argues Lisbeth Schorr, we have accumulated the knowledge necessary to reduce "rotten outcomes" for vulnerable children, but many administrators, academics, practitioners and public policy analysts are not aware of newly emerging insights, especially from outside their own fields. Schorr reports on a variety of successful programs that serve families whose children are vulnerable because they are growing up in poverty or with other environmental handicaps. The programs that have "changed the odds" for children in high-risk environments, Schorr discovered, typically offer comprehensive and intensive services, responding flexibly to a wide variety of needs; their staff have "the time and skill to establish relationships built on mutual respect and trust."

Schorr acknowledges that given our national tendency to look for one-shot interventions and to assume that what works for middle-class people should work for everybody, devising strategies for widespread replication is as difficult as devising a successful intervention in the first place. The challenges that must be addressed include: knowing what works; proving we can afford it; attracting and training enough skilled and commited personnel; resisting the lure of "replication through dilution;" surviving bureaucratization; and devising a variety of replication strategies.

Opportunities for Success: Cost Effective Programs for Children, Update, 1988—a report of the Select Committee on Children, Youth and Family, U.S. House of Representatives (Washington, D.C.: U.S. Government Printing Office, 1988) available from the Select Committee on Children, Youth and Families, 385 House Office Building Annex 2, Washington, D.C. 20515.

This bipartisan staff report makes use of more than 25 additional studies and information from hearings and investigations to update the Select Committee's 1985 review of the workability and effectiveness of eight preventive services. The highlighted programs include WIC, prenatal care, Medicaid, childhood immunization, preschool education, compensatory education, education for all handicapped children and youth employment and training.

Key cost benefit effects reported include: a $1 investment in the prenatal component of WIC has saved as much as $3 in short-term hospital costs; $1 spent on comprehensive prenatal care added to services for Medicaid recipients has saved $2 in the infant's first year; $1 spent on the Childhood Immunization Program saves $10 in later medical costs (yet smaller proportions of children were immunized against polio, measles and rubella in 1985 than in 1983), and early intervention programs in Colorado have saved $1560 per pupil in special education costs per handicapped pupil and $1050 per at-risk pupil.

The report includes an annotated bibliography of relevant research.

The First Sixty Months: The Next Steps—a joint product of the National Governor's Association Committee on Human Resources and Center for Policy Research and the Council of State Governments (Washington, D.C.: National Governors Association and Council of Governments, 1987) available from NGA, Hall of the States, 444 North Capitol Street, Washington, D.C. 20001 for $12.50.

This publication, a companion to the July, 1987 handbook *Focus on the First Sixty Months*, highlights 18 indicators of children's well-being in the states, permitting a comparison among states in each of nine regions, and permitting states to select one or more areas in which improvement is needed as a focus for attention and resources. The indicators are grouped under the major headings of mandatory kingergarten attendance; children in poverty; infant health (including infant mortality rate, percent of low-birthweight infants, and percent of pregnant women not receiving prenatal care in the first trimester); young mothers and young children (including number of births to teen mothers, numbers of teen mothers receiving AFDC, and percentage of working mothers with children under age 6); state and federal support programs; and indicators of long-term dependency. The authors of the report stress the need for data on children's deaths,

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National Center Notes

by Eleanor S. Szanton

At its recent spring meeting, the Board of Directors of NCCIP took a series of actions which we are pleased to report to the readership of *Zero to Three*.

Changes in leadership

The Board expressed its deep gratitude for the able leadership over the past three years of its outgoing President, **Sally Provence, M.D.** It welcomed to the presidency former President Elect **T. Berry Brazelton, M.D.**; and it elected for a three year term as Vice President, **Kathryn Barnard, Ph.D., R.N.**

New members of the Board.

The following individuals were elected to the Board of Directors:

- **Samuel J. Meisels, Ed.D.** Dr. Meisels is a professor at the School of Education and a research scientist at the Center for Human Growth and Development at the University of Michigan. His work on assessment measures has received the acclaim both of academicians and policy makers. He leads the expert team on Screening and Assessment issues which the National Center has undertaken for the National Early Childhood Technical Assistance System for the implementation of PL 99-457.

- **Ann P. Turnbull, Ed.D.** Dr. Turnbull is Professor in the Department of Special Education at the University of Kansas and Acting Associate Director of the Bureau of Child Research. The mother of a child with a developmental disability, she has written extensively on the experience of parents with the Education of the Handicapped Act. She is completing a one-year Kennedy Public Policy Fellowship in Mental Retardation. In this capacity, she has worked both in the U.S. Department of Education and with the Select Committee for Children, Youth and Families of the U.S. House of Representatives.

- **G. Gordon Williamson, Ph.D., OTR.** Dr. Williamson is Director of the Pediatric Rehabilitation Department at the John F. Kennedy Medical Center in Edison, New Jersey. He also serves as Associate Clinical Professor of Occupational Therapy at Columbia Presbyterian Medical Center. Dr. Williamson has been an outstanding researcher in the motor behavior of infants with handicapping conditions. He is author of a number of books and articles, the most recent one of which is *Children with Spina Bifida: Early Intervention and Preschool Programming*. He co-directs (with Dr. Shirley Zeitlin) the COPING Project.

We welcome all three of these individuals, each of whom brings academic distinction and strong concerns for the improvement of the lives of infants and toddlers and their families in this country.

National Center Fellows (1988-89)

The Board of Directors also approved the appointment of 15 individuals to NCCIP Fellowships for the coming year. Their names, disciplines and affiliations are listed below. (Second year fellows are marked with an asterisk.)

- ***Robin Adair, M.D.,** Pediatrics, Boston City Hospital
- **Zeynep Biringen, Ph.D.,** Developmental Clinical Psychology, University of Colorado
- **Alice Carter, M.A.,** Clinical Psychology, Yale Child Study Center
- **Francis Hickey, M.D.,** Pediatrics, Harvard Child Development Unit
- **Laurence Hirschberg, Ph.D.,** Clinical Psychology, Brown University, Bradley Hospital
- ***Marla Hooks, M.D.,** Psychiatry, Yale Child Study Center
- **Pauline Hopper, M.S.,** Developmental Psychology, Yale Department of Psychology
- ***Teresa Kohlenberg, M.D.,** Pediatrics, University of Massachusetts—Worcester
- ***Lorraine Kubicek, M.A.,** Human Development, University of Chicago
- ***Gilda Morelli, Ph.D.,** Development Psychology & Anthropology, University of Utah
- **David Oppenheim, Ph.D.,** Developmental Psychology, University of Utah
- **Sandra Petersen, M.A.,** Early Childhood Special Education & Clinical Psychology, University of California—S.F.
- **Randolph Potts, M.A.,** Cognitive Development, University of Chicago
- **John D. Rau, M.D.,** Pediatrics, Indiana University
- **Carol Rodning, Ph.D.,** Developmental Studies, University of California—L.A.

National Commission on Children

We are pleased to announce that three members of NCCIP's Board of Directors have been named to the National Commission on Children. This Commission is a special bipartisan task force created by Congress to identify ways to safeguard and enhance the physical, mental and emotional well-being of America's children and youth. The Commission will have 36 members, 12 already appointed by each of the two houses of Congress and 12 to be appointed by the White House. The Commission is charged with making recommendations for advancing a broad range of health, education, income security and social services for children. It is expected to report within the next year. NCCIP Board members who will serve on the Commission are **T. Berry Brazelton, Irving B. Harris,** and **Bernice Weissbourd.**

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preschooler immunization, demand for child care, children repeating the first grade, and the number of child-abuse victims, but these are currently unobtainable on a state-by-state basis.

The publication also includes case studies from Illinois, Maine, Missouri, New Jersey and South Carolina; these chronicle the steps these states went through to assess needs and to develop, implement, and evaluate a range of prevention programs for children from the prenatal period to five years of age.

Struggle To Be Borne—Kira Corser (photography) and Fran Adler (poetry) (San Diego, California: San Diego State University Press, 1988) available from March of Dimes, 675 N. First Street, #1200, San Jose, CA 95112 for $10.00.

In San Diego, California, as across the country, rising malpractice and low Medi-Cal (Medicaid) insurance rates mean that fewer and fewer obstetricians are delivering babies of poor women. In 1987, only 11 of more than 200 obstetricians in San Diego would deliver women covered by Medi-Cal insurance. Not surprisingly, community clinics staffed by nurse midwives had to turn away 643 women in January, 1987 alone.

Photographer Kira Corser and poet Fran Adler prepared an exhibit of photographs and poems designed "to penetrate the denial surrounding the crisis of thousands of women . . . who are pregnant, poor, and shut out from care." This 53-page book includes both photographs and poems. Adler draws from many sources for her poetry: she quotes mothers, C. Arden Miller's *Maternal Health and Infant Survival*, and obstetricians, as in the poem, "Not Fair."

I don't take women
with Medi-Cal insurance
for obstetrics. I have
a note posted in my office
to the effect that I don't feel
that I can provide
the quality of care
that I feel I have to provide
for the kind of reimbursement
I get from Medi-Cal.

And I don't feel
that I can increase my charges
to private patients
to make up for that.
I don't think it's fair.

Unnecessary Losses: Costs to Americans of the Lack of Family and Medical Leave—Roberta M. Spalter-Roth and Heidi Hartmann (Washington, D.C.: Institute for Women's Policy Research, 1988). Executive summary available for $4 and full report for $9 from the Institute for Women's Policy Research, 1400 20th Street, N.W., Suite 104, Washington, D.C. 20036.

This report, based on research funded by the Ford Foundation, examines the *current* costs or economic consequences to working women and men, to employers, to taxpayers and to society as a whole of three kinds of activities: caring for newly arrived children, caring for oneself or a family member during illness, and caring for elderly parents. The study examined a variety of indicators of costs and compared groups of individuals who experienced an event (e.g., childbirth or family illness) to a like group who did not have the experience. The report estimates that women who become mothers who have no parental leave lose an additional $607 million in earnings compared to women who have some leave, and such women cost taxpayers an additional $108 million in public assistance payments, for a total of $715 million annually. Even unpaid leave would reduce this loss, the report states, because workers who can go back to their former jobs will suffer less unemployment and earnings loss.

Medicaid Financing for Early Intervention Services: A Technical Report—Harriette B. Fox with Ruth Yoshpe (Washington, D.C.: Georgetown University Child Development Center, National Center for Networking Community Based Services, 1987) Available from CASSP, Georgetown University Child Development Center, 3800 Reservoir Road, N.W., Washington, D.C. 20007 for $8.00

The author of this report, funded by the Division of Maternal and Child Health, estimates that 30-35 percent of the more than 500,000 infants and toddlers potentially eligible for early intervention services under Part H of P.L. 99-457 will be Medicaid recipients. Among the allowable Medicaid services that may be furnished to these children are many of the early intervention services required by infants and toddlers. Federal law mandates the availability of certain services, including outpatient hospital services and EPSDT (Early and Periodic Screening, Diagnosis and Treatment). States also have the option to cover clinic services, home health services, case management, private duty nursing and the services of physical, speech and occupational therapists, psychologists and social workers.

The report reviews statutory requirements concerning Part H funding, analyzes the financing arrangements of existing early intervention programs, discusses opportunities for covering medical and health-related early intervention services under Medicaid, and discusses issues that will need resolution by Medicaid, Title V and Part H agencies. Appendices describe children's eligibility policies under Medicaid and provide a glossary of Medicaid terms.

Handbook of Autism and Pervasive Developmental Disorders—Donald J. Cohen and Anne M. Donnellan, editors (New York, NY: John Wiley & Sons, 1987). $55.00

This *Handbook* is designed to help the various professionals involved with autism and pervasive developmental disorders to understand each other's perspectives and contributions, in the hope that increased collaboration will improve the treatment and long-term understandings of autistic individuals.

The editors note the expansion in knowledge and services over the past decade but also recognize that "fundamental improvement in the long-term outcome of autism depends on increased knowledge about brain development and the variety of ways in which development of social and communicative capacities can be derailed." The volume's 54 chapters are divided into sections on characteristics of autistic syndromes, interventions, autism and society, and perspectives. Issues in the classification of pervasive developmental disorders and associated conditions are discussed in chapters by Donald Cohen, Rhea Paul and Fred Volkmar and by Sally Provence and E. Kirsten Dahl. Public policy and advocacy issues are discussed in chapters by Joanna Erikson, Frank Warren and Ruth Sullivan, among others.

Assessment and Diagnosis in Child Psychopathology—Michael Rutter, A. Hussain Tuma, and Irma Lann, editors (New York: The Guilford Press, 1988) $35.00.

This volume is based on an NIMH-sponsored workshop that brought together researchers who had worked with the World Health Organization's diagnostic and classification system, ICD-9, and with the American Psychiatric Association's system, DSM-III, as well as other investigators. Chapters address issues involving the two systems and their successors, measurement instruments, and problems of syndrome definition and validation. In discussing outstanding issues in diagnosis and classification, Michael Rutter and A. Hussain Tuma note that "we lack an adequate scheme for diagnosing disorders in very young children (outside the realm of autistic conditions). The new social categories of attachment disorders help, but they do not encompass the bulk of problems in this age period. Once more, further research is indicated."

Children and Families: Studies in Prevention and Intervention—Euthymia D. Hibbs, editor (Madison, CT: International Universities Press, 1988) $65.00.

In the summer of 1984, agency representatives, scholars and specialists in a variety of health care fields gathered at a world conference on "Infancy as Prevention," held in Athens, Greece. This book contains papers presented at the conference, including the work of 72 contributors from eight counties. Papers address topics in the areas of prevention, intervention, parent-infant interaction, cognition and education, health and behavior, day care, the impaired child, adoption, and the family.

In his paper on "Implications for Intervention and Service Delivery: Cross-Cultural Considerations," the late Reginald S. Lourie reminds readers that "in any depriving culture where survival has priority, there is a developmental cost." He notes that to develop appropriately, very young children in any culture need to experience "relatedness and calmness, dependency and trust with comforting and closeness, pleasure and joy, enthusiasm, interest and attentiveness, assertiveness with explorativeness and curiosity, protest about distinct forms of unpleasure and anger, self-limit-setting and using rules, as well as empathy and affection."

The Psychology of Separation and Loss: Perspectives on Development, Life Transitions and Clinical Practice—Jonathan Bloom-Feshbach, Sally Bloom-Feshbach, and Associates (San Francisco, CA: Jossey-Bass, Inc., 1987) $37.95.

The authors of this volume describe separation as "an experience, a developmental process, a dimension of life transitions, a symbolic mental event." Contributors to the volume were invited to incorporate relevant theory and research into their discussions and, where appropriate, to provide clinical illustration. The first section of the book, on the role of separation in development, includes a chapter by Sally Provence on psychoanalytic views of separation in infancy and early childhood and one by Alicia Lieberman on contributions of attachment theory and psychoanalysis to the study of separation in early life. The second part of the volume, on separation and loss in major life transitions, includes a chapter on the effect of work-related separations on children and families by Chaya S. Piotrkowski and Lisa K. Gornick and on the death of a parent or sibling during childhood by Janice Krupnick and Fredric Solomon. A third section of the book addresses implications for treatment, when experiences of separation and loss have resulted in psychopathology.

Families in Transition: Primary Prevention Programs That Work, Primary Prevention of Psychopathology Vol. XI—Lynne A. Bond and Barry M. Wagner, editors (Newbury Park, CA: Sage Publications, 1988) $35.00.

This volume, the eleventh to emanate from the Vermont Conference on the Primary Prevention of Psychopathology, describes fully operating programs that have been evaluated and demonstrated to be effective. The family transitions that are addressed by the programs include both those that are "normative" and those that are "non-normative." Addressing the normative experience of childbirth, Sandra Mitchell, Diane Magyary, Kathryn Barnard, Georgina Summer and Cathryn Booth report on two models of home-based prevention programs for families of newborns: a mental health service delivery model, which emphasizes a process approach to maternal-child competence, and an information and resource utilization model, which is characteristic of traditional public health efforts. Addressing the non-normative experience of coping with a child's chronic illness, Ruth Stein, Dorothy, Jones Jessop and Henry Ireys seek to describe a broad range of preventive and promotive interventions and to outline and analyze strategies that enhance coordination and continuity of care, social support, and cognitive competence in children and families.

Starting Early: A Guide to Federal Resources in Maternal and Child Health—National Center for Education in Maternal and Child Health (Washington, D.C.: NCEMCH, January, 1988) Single copies available free of charge from the National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, D.C., 20057.

This 167-page book has been developed to help health professionals locate information services, materials, and programs that can assist in their delivery of health education and services. *Starting Early* includes an annotated listing of more than 80 Federal agencies and information centers that provide information services related to maternal and child; a description of more than 500 publications and audiovisual materials, including ordering information; and a directory of Federal, regional, and State maternal and child health programs, including programs for children with special health care needs, and regional genetics services networks.

ROBERT MAUST

Slow Grows the Child: Psychosocial Aspects of Growth Delay—Brian Stabler and Louis Underwood, editors (Hillsdale, New Jersey: Lawrence Erlbaum Associates, 1986) $19.95.

This volume represents the proceedings of an October, 1984 symposium on psychosocial aspects of growth delay that included researchers and practitioners in medicine, psychology and social work. Among the 14 chapters, the contribution by Dennis Drotar, "Environmentally Based Failure to Thrive: Diagnostic Subtypes and Early Prognosis," suggests that early onset (before 6 months of age) FTT may represent a distinct subtype that is indicative of more compromised family resources and/or parent-child relationships than later onset FTT. Given early onset, early identification and treatment may improve psychological outcomes for these children. Diane Rotnem's essay, "Size versus Age: Ambiguities in Parenting Short-Statured Children," attempts to understand the developmental patterns of short-statured children within the context of their parenting and social experience and to suggest long-term collaboration among professionals, children and parents to develop effective strategies for coping with social influences resulting from growth delay.

Adolescent Mothers in Later Life—Frank F. Furstenberg, Jr., J. Brooks-Gunn, S. Philip Morgan (New York: Cambridge University Press, 1987) $27.95.

This volume reports findings from a 17-year follow-up of nearly 300 adolescent mothers from Baltimore and their children, the only investigation to date that has traced the life course of adolescent parents from first pregnancy to later adulthood, looking at both parents and their children. The authors found a tremendous diversity in the long-term adaptation to early childbearing. In contrast to the common undifferentiated negative image of the teenage mother, the study found that many adolescent mothers return to school after dropping out, find employment ater a stay on welfare, and curtail fertility after one or two additional births.

The offspring of the adolescent mothers also encountered a great diversity of life experience. However, many of their childhoods were characterized by change—in residential patterns, in child care, and in adult male support. About 10% were living with neither biological parent at follow-up, and almost a third of the children had been separated from their mothers for part of their childhoods, frequently because of the mother's educational or career priorities. Shared caregiving was common; at the 5-year follow-up almost half of the pre-schoolers had another adult spending as much time caaring for them as their mother. Long-term shared child-care arrangements seemed to confer neither positive nor negative effects for the children.

The authors recommend greater sensitivity in policymaking and programming to developmental differences within the population of adolescent parents and at different points in the life span. The study results suggest, they note, that individual teenage mothers may require very different kinds of assistance, that success may come *after* adolescence, and that the timing and sequencing of services may be critical to their impact. The most high-risk adolescents may be the most difficult to serve, but they may also benefit most from programs sufficiently intensive and comprehensive to compensate for the relative paucity of assistance provided by their families and their relatively greater neediness.

Meeting the Medical Bills is a 25-minute VHS videotape, produced by the National Center for Clinical Infant Programs with assistance from private donors and the U.S. Office of Maternal and Child Health, that features excerpts from a talk by Julie Beckett at a meeting of parents connected with Project Zero to Three.

Ms. Beckett, who has helped to bring about major changes in Medicaid funding for children with special health care needs, discusses: Medicaid waivers that finance home care for children with special health care needs; Supplemental Security Income (SSI) as a source of regular monthly income for some children with special needs; and working with private insurance companies to obtain the best possible coverage for children. The video is intended for use as a starting point for group discussions of financing medical bills and is accompanied by informational brochures and a background reading packet.

To order a copy of the videotape plus accompanying printed information, send a check for $10.95 made out to NCCIP/Med Video to "Meeting the Medical Bills," P.O. Box 1492, Washington, D.C. 20013 or call the National Information Center for Handicapped Children and Youth, 1-800-999-5599.

Conference Call

July, 1988

July 11-15: *The Mississippi University Affiliated Program at the University of Southern Mississippi* will sponsor its Third Annual Developmental Disabilities Training Institute entitled "Implementing P.L. 99-457; Intervention Procedures for Infants, Toddlers and Preschoolers with Handicaps." The Institute will be held on the Mississippi Gulf Coast and will focus on ecological assessment and curriculum linkage, family service delivery practices, individual family service plans, and least restrictive environment and transition. Contact Dr. Jane Z. Siders, University of Southern Mississippi, Box 5163, Hattiesburg, MS 39406-5163, tel: (601) 266-5163.

July 11-15, August 1-5: *Child Development Resources* will hold its Third Annual Early Intervention Summer Institute in July in Denver, Colorado and in August in Williamsburg, Virginia. The theme will be "Integrating Service Delivery: Policy, Ethics and the IFSP." Write to Child Development Resources, Inc., P.O. Box 299, 6325 Centerville Rd., Lightfoot, VA 23090.

July 21-22: *Project SUNRISE* of the *Western Carolina Center* will present a national training institute at Hilton Head Island, South Carolina entitled "Training for Excellence: Strategies for the Future in Early Intervention." For information contact Renae Emrani, Project SUNRISE, Family, Infant and Preschool Program, Western Carolina Center, 300 Enola Road, Morganton, NC 28655, tel: (704) 433-2865.

July 28-30: The third biennial *NCAST Institute,* entitled "Players and Process: Bringing about Change in Organizations and Individuals," will be held in Seattle, Washington. Speakers addressing the theme of changing organizations will include Everett Rodgers, Anita Spietz, Margery Robison, Kathy Peppe, Connie Lybarger, and Charlene Snyder. Kathryn Barnard, Kristin Swanson-Kauffman, Claudia Spencer, Betty Sullivan, and Anita Spietz will discuss changing individuals. Cathryn Booth, Patricia Brandt, Anita Spietz, and Kathryn Barnard will describe assessment for change. Write or call NCAST, University of Washington, WJ-10, Seattle, WA 98195, tel: (206) 543-8528.

August, 1988

August 3-6: The *National Association for Family Day Care* will hold its fourth bi-annual conference in San Mateo, California. London Smith will be the keynote speaker. For information write to NAFDC, 815 15th Street, N.W., Suite 928, Washington, DC 20005 or call Neva Duncan at (408) 923-4872.

August 23-26: The *Infant-Parent Institute* will present the 8th annual Brief Summer Course in Infant Mental Health on the campus of the University of Illinois at Urbana-Champaign. Case material will guide discussion on the nature of attachment in infancy, how families prepare for the arrival of a baby, problems of infant-parent "fit," and a particular theory and method of assessment and treatment. Michael Trout will be principal instructor. Contact Mr. Trout at the Infant-Parent Institute, 501 South, Champaign, IL 61820, tel: (217) 352-4060.

September, 1988

September 7-9: *The Federal Interagency Coordinating Council*, the *Bureau of Maternal and Child Health and Resources Development*, the *American Academy of Pediatrics* and the *National Maternal and Child Health Resource Center* will sponsor a U.S. Surgeon General's Conference in Washington, D.C. on the theme "Building Community-Based Service Systems for Children with Special Health Care Needs." Conference plenary sessions and workshops will focus on the population in need of services, the services that are needed and the organization of services. For further information, contact the National Maternal and Child Health Resource Center, College of Law, The University of Iowa, Iowa City, IA 52242, tel: (319) 335-9067.

September 22-25: The *International Association for Infant Mental Health*, the *Brown University Program in Medicine* and *Bradley Hospital* will sponsor a conference in Providence, Rhode Island on the theme "At Risk Infants and At Risk Families." Plenary speakers will include Maria Barrera, Robert Emde, Maureen Hack, Arnold Sameroff, Klaus Minde, Daniel Stern and Lewis P. Lipsitt. For information contact Janice Miller, Brown University Program in Medicine, Office of Continuing Education, Box "G", Providence, RI 02912, tel: (401) 863-3337.

September 23-24: *Helping After Neonatal Death (HAND)*, the *National Perinatal Bereavement Alliance*, and the *Mid-Coastal California Perinatal Outreach Program* will sponsor the sixth national conference on miscarriage, stillbirth and newborn death, entitled "A Special Grief: The Death of a Baby." The conference will take place in Redwood City, California (San Francisco Bay Area). Plenary speakers will address issues of merging parental expectations and medical reality, integrating the role of the professional and grief, what parents want caregivers to know, and ethical and perinatal decision making. Contact Elizabeth Patterson, Stanford University Medical Center, 750 Welch Road, Suite 120, Palo Alto, CA 94304, tel: (415) 723-5763.

September 25-28: *Parent Care, Inc.* will hold its 5th annual conference in Newport Beach, California. The conference is designed for both parents and caregivers and will cover prenatal, neonatal, and post-discharge issues concerning the critically ill newborn. For more information call co-chairs Dottie Andrews or Ralph Rucker at (714) 532-8688.

September 30-October 1: The *C.M. Hincks Institute* and the *World Association for Infant Psychiatry and Allied Disciplines (WAIPAD)* will sponsor a multidisciplinary symposium in Toronto, Ontario on "Infancy: Intrapsychic and Interpersonal Life Cycles." Speakers and discussants will include Kathryn Barnard, John Byng-Hall, Peter de Chateau, Robert Emde, Yvon Gauthier, Serge Lebovici, Klaus Minde, Joy Osofsky, and Daniel Stern. Write or call Edythe Nerlich, C.M. Hincks Institute, 400 Jarvis Street, Toronto, Ontario M4Y 2H4, Canada, tel: (416) 924-1164.

October, 1988

October 6-9: The *Family Resource Coalition* will hold its National Conference in Chicago. Keynote speakers will include Edward Zigler, Bernice Weissbourd, T. Berry Brazelton, Anna Quindlen, William Julius Wilson, and Hon. George Miller. The conference will also include more than 100 workshops, half-day focus sessions, seminars, a video film theater, exhibits, and a program showcase. Write or call Family Resource Coalition, 230 N. Michigan Ave., Suite 1625, Chicago, IL 60601, tel: (312) 726-4750.

October 14: The *Illinois Association for Infant Mental Health* will hold its sixth annual conference in Chicago, on the theme "Against All Odds: Bringing Success into the Lives of Multirisk Infants and Families." Alicia Lieberman will be the keynote speaker. For information, contact Barbra Lancelot, Illinois Institute for Developmental Disabilities, 1640 West Roosevelt Road, Chicago, IL 60608, tel: (312) 413-1567.

October 26-30: The *American Academy of Child and Adolescent Psychiatry* and the *Canadian Academy of Child Psychiatry* will hold a joint annual meeting in Seattle. Sessions will address prevention, research, diagnosis and treatment of psychiatric illnesses affecting children, adolescents and their families. Contact AACAP, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016, tel: (202) 966-7300.

November, 1988

November 13-16: The *Council for Exceptional Children's Division for Early Childhood* will sponsor an international early childhood conference on children with special needs in Nashville, Tennessee. Frances Degen Horowitz and Michael J. Guralnick will address general sessions. Twelve pre-conference workshops will address assessment of children's play, a systems approach to program evaluation, care for chronically ill children from birth to 18 months, meeting family needs, and parent-infant interaction, among other topics. For further information write to the Division for Early Childhood, The Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091.

November 17-18: The *Women's Hospital at AMI St. Luke's* will hold a symposium in Denver, Colorado entitled "The Evolution of Infant Interaction: From Research to Reality." Faculty will include T. Berry Brazelton, Marianne Neifert, Richard Krugman, James Strain and Robert Emde. Contact Women's Hospital at AMI St. Luke's, 601 E. 19th Avenue, Denver, CO 80203, tel: (303) 839-6636.

Zero to Three: A Topical Index for Volume VIII

This index groups by topic the articles and reviews of publications that have appeared in *Zero to Three* from September, 1987 through June 1988. When an item is listed as "review of" this means that a brief summary of the publication appears in the issue of *Zero to Three* indicated.

Copies of the index for Volumes I through VII are available on request from the National Center. Back issues of *Zero to Three* are available for $4 each from the National Center for Clinical Infant Programs, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005. Payment must accompany orders. NCCIP reserve the right to supply photocopies of issues no longer in print.

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